University of Alberta

Gestational diabetes: The meaning of an "at risk" pregnancy

by

Marilyn Kathleen Evans

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

Department of Nursing

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Abstract

Pregnancy is a normal developmental process that encompasses a multitude of changes for women and their families. New reproductive technologies and scientific advances have altered how women and health professionals view pregnancy by introducing the concept of being "at risk" within the childbearing process. Women with gestational diabetes mellitus (GDM), in addition to the natural changes related to pregnancy, are required to undergo considerable technical and life style adjustments to reduce the incidence of perinatal and neonatal morbidity. Being diagnosed with GDM is coupled with the implication that the woman and her fetus are at risk. Although these women may not experience any increased physical discomfort, they may feel compelled to identify themselves as high-risk to ensure a safe birth and healthy baby.

The intent of the research question, what is the meaning of being at risk for pregnant women, is to gain an in-depth understanding of GDM as pregnant women meaningfully experience it. A hermeneutic phenomenological approach was used to reveal the meanings embedded in women's experiences of becoming diabetic during pregnancy. Conversational interviews, the first during pregnancy and the second between six to eight weeks postpartum, were conducted with eleven women who had gestational diabetes. One pregnant woman with Type I diabetes also participated. Data analysis involved a reflective process consistent with the guidelines of thematic analysis.

Four themes identified as characteristic of their pregnancy experience were: living a controlled pregnancy, balancing, being a responsible mother, and being transformed. The findings inform health care professionals about the complexities of a pregnancy experience afflicted with diabetes and challenge them to openly discuss and reassess their present models of care for pregnant women and their families. Implications for nursing practice and recommendations for further research are discussed.

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CHAPTER ONE

To live the "public" pregnancy

When enough women realize that birth is a time of great opportunities to get in touch with their true power, and when they are willing to assume responsibility for this, we will reclaim the power of birth and help move technology where it belongs-in the service of birthing women and not as their master (Northup, 1994, p. 413).

Childbearing today has shifted from women's personal and private domain to become increasingly part of the public realm. Prior to the widespread use of reproductive technologies in health care, pregnant women's knowledge of their own well-being and that of their fetus was limited to inferences made from the physical signs and symptoms of pregnancy (Sandelowski & Perry-Black, 1994). Women would acknowledge and interpret their own bodily signs, such as a missed period, nausea, weight gain, enlarged abdomen, tender breasts and quickening (fetal movements) to help determine their pregnancy status. Duden (1991) suggests there is a certain point based on what a woman feels internally rather than what is ascertained by objective external measures that tells her that yes, she may be pregnant. Upon encountering certain somatic symptoms and physical signs women who have contemplated getting pregnant or have tried to conceive will inevitably consider themselves as being pregnant.

Today many women attend to their bodily signs that suggest a possible pregnancy as a precursor for seeking professional validation and expert opinion about the likelihood of having conceived. For example, a woman will go to a health professional or buy a self-administered pregnancy test with the thought; *I think I am pregnant,* and seek an answer to the question, *but am I pregnant?* To obtain pregnancy confirmation from external sources suggests that knowledge based on medical technology is more authentic than that which is based on a woman's intuition.

Questions concerning the nature of the childbearing experience for pregnant women in a highly technical health care world are addressed in this study. With the development of gestational diabetes during pregnancy the woman is classified as "at risk". How does the woman maintain a sense of normality when she encounters the

notion of risk in pregnancy? What does it mean to live the pregnant body that is judged technologically as "at risk"? How does a pregnant woman if considered "at risk" exercise her autonomy and self-determination throughout her childbearing experience?

Pregnancy has been transformed by today's health care system into a highly technical process in need of external authority and control to help identify and reduce any associated risks. Childbearing depicts a time in a woman's life in which external judgment and interventions are sanctioned to help prevent adverse maternal and neonatal outcomes. "The most characteristic of modern antepartal care is the clinical insistence on the probability of pathology in all childbearing" (Oakley, 1986, p. 2). Viewing pregnancy as potentially or actually pathological influences the beliefs, policies, and practices held by the public, legal institutions, governments, health professionals and women themselves about the childbearing process.

In response to the medical discourse of pregnancy as an illness, a woman's pregnant body is subjected to technological interventions in reproductive health. The ideology of reproductive technology promotes a mechanical view of a woman's pregnant body as an object that can be examined and manipulated in order to produce a healthy baby. Consequently, pregnancy is placed within a curative model of medical intervention and considered a condition that needs explanation and control rather than a naturally occurring event. One's self-identity as a pregnant woman is undermined with the implication that impending motherhood is a condition of risk that requires investigative and curative measures (Oakley, 1993).

Pregnant embodiment

Pregnancy is a normal developmental process that encompasses a multitude of changes for women and their families. Women's experiences during pregnancy are unique, contextual and socially constructed through their encounters within both formal and informal societal structures. Although women will experience many transformations throughout their pregnancy, they remain autonomous and self-governing beings.

With pregnancy a woman's customary bodily self begins to change. The body being considered here is not one that is separate from the self, being an object in

nature, as conceptualized by dualism. Rather, the body is seen as embodied, being different from, but not inseparable from the self (Gadow, 1980). This lived body reflects a person's way of being in the world and represents the unity of self and body existence.

Gadow (1980) asserts that embodiment is the essence of being human. An assumption of embodiment is that all parts of the body are fundamental to being human and cannot be separated from one another (Wilde, 1999). Human embodiment can be defined as experiencing and understanding the world through our lived bodily experiences. The nature of embodiment involves both *having* and *being* a body. Our lived bodily experiences include the usual events of the everyday world that we take for granted and which are not readily available to our self-awareness. For example, as a woman goes through her usual daily tasks in life prior to conception, her body is primarily left unnoticed. It functions in a state of familiarity to the woman's self. The experience of her body is "passed over in silence" (Sartre as cited in Van Manen, 1998, p.11) or hidden from her conscious mind unless an illness or injury is experienced. Gadow describes this lived bodily experience as being immediate or direct, that is, the person experiences a sense of self-body unity, a characteristic that is present during times of healthy functioning.

Merleau-Ponty (1962) describes the body as having two aspects, being an object for others and a subject for self, i.e. to be acted upon or having the ability to act. Similarly, in her dialectic model of body and self, Gadow (1980) suggests when in a state of good health a person understands his/her self-body as "being capable of affecting the world, as well as the consciousness of being vulnerable to the world's impact" (p. 174). The experience of the lived body resembles what Van Manen (1998) refers to as "a kind of unaware awareness"(p.11). According to Birke (1999) living your body means experiencing it as transformable through both social structures and internal biological events. It is when the self-body experiences itself as acting upon or being acted upon by a part of itself rather than the world in which the self-body is situated that a person will experience diminished agency and greater vulnerability (Gadow, 1980). At times of illness, for example, our everyday lived

experience in which the embodied self is taken for granted breaks down (Leonard, 1994).

Duden (1991) asserts women's descriptions of their body and its various forms are culturally constructed. In modern times a women's pregnant body was envisioned as the effect and object of medical examination. A pregnant body is envisioned as an entity to be probed, reduced, measured, abused and subjugated. Foucault's (1980) metaphor of panopticon (constant surveillance and scrutiny of individuals through the gaze of others) relates to the proliferation of prenatal testing and interventions that are prevalent in present day obstetrical care. A woman's pregnant body has become subject to the "clinical gaze" of others transforming the self-body relation into a succinct object. It is the clinical view of a woman's body as being as separate from her self and a product of medical examination that determines the well-being of the pregnancy, the pregnant woman and her unborn anticipated child.

Human beings exist separate from each other and are confined to their own individual body. Although pregnancy, the pregnant body and the fetus can be easily objectified, analyzed and managed says Bergum (1997) "pregnant women's embodied experience is not easily articulated" (p.143). In pregnancy there are two entities, a woman and a fetus, both inhabiting the one body, that of the woman. In the highly technological world the view of a woman and her fetus as separate beings perpetuates the view of the fetus as patient and the woman as a mere container. "In the medical paradigm visualizing the female pregnant body is important for diagnostic purposes and the development of prenatal technologies is associated with constructing the unborn as a subject distinct and separate from its mother" (Kent, 2000, p. 6). Distinguishing the woman and her fetus as separate entities permits the use of surveillance and monitoring at the expense of the mother's self-determination.

Pregnant embodiment involves the woman experiencing her body as herself yet not solely herself (Young, 1984). The physical growth and movements of the fetus within the mother's body depicts a notion of separateness. Yet the pregnancy experience Bergum (1997) suggests, involves a relationship as "one with the other"

(p. 144) rather than being two separate opposing entities. The fetus's presence is not detached from the mother's being, but is part of the mother's lived experience of her pregnant body. The connection between the mother and the fetus is a unique and intimate one with the baby felt as an entity nestled deep within the confines of its mother's womb but experienced as part of the mother's self-body. Rothman (2000) describes pregnancy as a physical, social and emotional relationship between the mother and her fetus. During pregnancy a woman undertakes the maternal task of binding-in to her anticipated child that involves a fusion of self and fetus making it difficult for the woman to separate self from her expected child (Rubin, 1984). Theirs is a fluid and reciprocal relationship in that what happens to one affects the other. It is only after birth when there's physical separation of self (mother) and other (fetus) that the unique "oneness" experienced in their prenatal relationship ends.

Once she receives validation of her pregnancy a woman begins to experience a change in her bodily relation with self and others. She moves from questioning if she is pregnant to state, "*I'm pregnant.*" The blurring of body boundaries undermines the integrity of the pregnant body and leaves the woman with "no firm sense of where she ends and the world begins" (Young, 1984, p. 49). The pregnant woman develops a heightened sense of the body that she is and the body that she has. The missed periods, the nausea, tingling breasts, fatigue and other physical symptoms are brought together to become something meaningful. There is a reason for these bodily experiences. She is pregnant and about to commence on a journey of becoming a mother.

Van Manen (1998) suggests that in a state of ill health the accustomed unity of the self-body relation becomes disturbed. The taken-for-granted lived experience of the self-body unity is interrupted with a sense of chaos and uneasiness. The body in illness becomes "object" to the self and "something that confronts us" (Van Manen, 1998, p. 12), almost adversarial. The body develops a sense of agency and action. Although not considered pathological, the natural changes associated with pregnancy presents a situation in which the woman's relationship with her customary body is altered. Some women experience dis-ease and dis-comfort while others experience enhanced-ease.

Pregnancy is associated with a woman's loss of control over her lived body. The pregnant body takes on a sense of agency as it transforms physically and presents with unfamiliar symptoms. The rapidly changing body, unfamiliar physical sensations and hormonal activities mean that new bodily experiences are superimposed upon and supersede the familiar self-body relation. The physical and emotional changes intrinsic to pregnancy influences the woman's familiar lived body experience. As her pregnancy progresses the woman will encounter a loss of mastery over her body. She experiences her abdomen growing to accommodate the fetus within, her breasts enlarging in preparation for nursing, her hands and feet swelling in response to internal physiological changes, her bladder with heightened sensitivity and in need of frequent emptying. These are all the "body's expression of its own determination, aim or purpose" (Gadow, 1980, p.180).

Part of the woman's internal bodily experience and her interpretation of that experience are shaped by the society in which she lives (Birke, 1999). The invasive surveillance a pregnant woman may encounter from health professionals, family and friends serves as a reminder that she is no longer in control of her own body or life experience. A woman's pregnancy, her pregnant body and how she personifies her impending motherhood are shared not only with the entity that lies within but also with others.

The enlarging abdomen of the pregnant body is a visual signal to others of a woman's imminent motherhood. Duden (1993) presents two stories regarding the female body during pregnancy. One concerns the body as seen from the outside by the health professional and the woman herself. It deals with the pregnant body as object, "as her flesh and being is or can be exposed to another gaze" (Duden, 1993, p.8). To experience her body as a thing gives the notion of being acted upon and leaves the woman "uncertain of her body's capacities ... and she does not feel that its motions are entirely under her control" (Young, 1990, p. 150). Young further suggests that living a bodily existence as object emphasizes passiveness and leaves the woman inhibited and not constitutive of her own intentions. The other story pertains to what lies hidden within the confines of the womb. During the first few weeks of pregnancy the bodily changes occurring within the pregnant woman are

hidden from the outside world. It is a private story known only to the woman living it and remains concealed until it becomes exposed to the outside world through technological means, the woman's revelation, or both.

Scientific progress in reproductive technology has facilitated the perception of pregnancy as a disease state that requires external control and interventions to achieve optimal maternal and neonatal outcomes. In response to this notion, Duden (1991) suggests:

> Somehow it is as if women transform themselves into uterine environments that have to be monitored in order that everything goes right. The machinery in a way invades the body and invades the senses so women cannot trust their own senses (p. 8).

Pregnancy brings forth a flurry of uncertainties that necessitate a revision of the woman's feminine identity and a new relationship to her now pregnant body with its both unseen and explicit changes (Raphael-Leff, 1991). An element of anxiety about the normality of her pregnancy experience and her fetus remains until the woman has delivered and can see and hold her baby. Mercer (1995) suggests that many pregnant women's thoughts are directed towards threats to her self-body unity and efforts to reduce the uncertainty and gain some sense of how she will manage her pregnancy experience. She may begin to wonder, *is my pregnancy normal? What are these twitches that I feel? Is my baby OK? Am I going to get through this? Am I doing the right things for my baby and myself?*

The view that pregnancy is a biological process to be closely managed limits a woman's expressed individuality. One mandate of antepartal care is to identify and avoid problems by instituting prophylactic measures to treat conditions considered harmful for the mother and the fetus. The decision to undergo prenatal testing is determined not only by adherence to societal norms but also by a woman's need for reassurance about her well-being and her pregnancy. Ongoing prenatal assessment provides information on how well the pregnancy and fetus is progressing. Health professionals act as intermediaries between a woman and her fetus and relay information about the fetus that is largely inaccessible if left to the sole device of the mother-to-be. A mother comes to experience her pregnant body as object and more

importantly something that she struggles to control with consideration that what she does or does not do can influence her own and her baby's health as well as present and future well-being.

A pregnant mother finds herself divided between meeting external forces (government policies, health care professionals, family, and friends) who may want to monitor her pregnancy and attending to her own embodied pregnancy experience. It is a woman's acceptance of the medical ideology says Duden (1993) that leads to disembodiment and forces a woman into, "a nine month clientage in which her scientifically defined needs for help and counsel are addressed by professionals" (p. 4). Health professionals set the norms regarding how much weight should be gained, how well the fetus is growing, how the pregnancy affects the body, how the pregnancy affects the fetus and the mother, and when the time is best for the birth. Raphael-Leff (1991) in speaking of the health care provider says, "their importance lies in their ability to gain and share with her, their understanding of the unknown, what and who is happening inside her." (p. 138). *But where is her voice? Are her needs heard? Is her pregnancy as she experiences it acknowledged and understood?* When the woman as subject no longer exists as a result of imposing objectification by self or other, she becomes annihilated (Gadow, 1994).

Being a pregnant body "at risk"

Advances in reproductive health and technology are associated with the medicalization of women's bodies and experiences. Within a medical narrative the pregnant woman's body is viewed as pure object, thus minimizing the existence of her body as subject (Gadow, 1994). New reproductive technologies and scientific advances have altered how pregnant women view their pregnancy by introducing the concept of being "at risk" to the childbearing process. The pregnancy experience has transformed from what was considered a natural life occurrence into a condition where risk is emphasized. The woman is considered a potential risk to both herself and her fetus. In addition, the pregnant state is emphasized as a risk to the mother and her fetus. This subtle shift from pregnancy being acknowledged as a natural process that requires minimal external interventions to being considered a risky business that warrants monitoring, control and certain curative measures may have

consequences for the well- being and comfort level of pregnant women and their families.

In our previous work exploring women's pregnancy experiences, the concept "*perinatal comfort and well-being*" was found related to the inner strength of pregnant women and how their communities view them (O'Brien, Evans, & Medves, 1999). Perinatal comfort and well being is perceived as multidimensional and includes the physical, social, psychological, and spiritual aspects of being for pregnant women and their families. A woman's optimal level of comfort and well-being is influenced by mutual respect, personal control, informed choice, autonomous decision-making, and freedom from anxiety about her health and that of her fetus.

It is often assumed that pregnant women are unhealthy and not able to be fully autonomous decision makers regarding what is best for their pregnancy and fetus (Donahue, 1993). As women's bodies and pregnancies are medicalized, prenatal diagnostic testing and screening, prenatal surveillance and fetal monitoring become the accepted societal norm for clinical practice. The medicalization of pregnancy, suggests Oakley (1986), has placed childbearing under the auspices of social policies, institutions and health care professionals. The emphasis of "risk" in pregnancy offers rationale for the medical community to introduce the use of innovative diagnostic techniques, screening tests and clinical interventions throughout the childbearing period. Adherence to a medical paradigm upholds the argument that risk to the fetus is justification for pregnant women to comply with prenatal diagnostic testing and certain treatment regimes (Kaufert & O'Neill, 1993). It is pursuant of women as passive participants in medically controlled events of pregnancy and childbirth says Sherwin (1992) that feeds the growing notion of a pregnant woman as being a genuine threat to the well-being of her fetus. Pregnancy becomes an event in which women are not deemed capable of exercising their autonomy except at the expense of their fetus. As a result, women are not encouraged to view their pregnancy as a normal healthy state but rather as a situation that is at risk, réal or potential.

Prenatal monitoring is a culturally approved means for women to assure themselves and others that they are doing all that can be done during their pregnancy to produce a healthy infant. Surveillance and control has become a normalized

dimension of a woman's pregnancy experience. At the same time De Koninck (1998) proposes that women themselves offer endorsement of medical interventions during pregnancy. She further argues that medicalization of pregnancy negatively affects women's images of themselves as being capable of producing a healthy child and heightens the perceived significance of medical interventions for ensuring a positive pregnancy outcome. It is this increasing emphasis on strict monitoring of pregnancy according to "constantly evolving medical criteria" and "the supervision of pregnant women's habits" (De Koninck, 1998, p. 153) that places a moral responsibility upon the mother to act in certain ways during pregnancy.

Modern discourse on risk corresponds with an approach that controls a person's behaviors and health care practices to identify and reduce their actual or perceived level of risk. Pregnancies that are determined by technology as progressing normally are often considered at low risk. Health professionals classify as high risk those pregnancies that are adversely affected by certain physiological, psychological and environmental factors. These factors in conjunction with the implication of being "at risk" present real or potential threats to the comfort and well being of pregnant women and their families. For a woman to encounter complications during her pregnancy heightens the presence of uncertainties and intensifies her changing self-body relationship.

The pregnancy experience is a progression of events analogous to taking a journey. A journey implies travel or movement from one place to another. There is a beginning and an end to any journey but the middle is often filled with challenges to overcome and many unknowns to discover. The start of a journey could be when the person physically embarks on a trip, as in getting on a plane, into a car, or perhaps taking off on foot. At other times the mere decision to go on a trip marks its' beginning. Sometimes a journey will commence quite unexpectedly with little prior planning or thought. Whatever the starting point though, usually some questions are asked, such as, how will I get there, what do I need to take, who will go with me. How long will it take? What events might I encounter?

The endpoint of a journey may be known before commencement; for example, a person has a pre-determined destination to reach. Alternatively a person's final

destination may be unknown at the outset leaving the end of the process largely ambiguous. Although you may know your final destination as you start out a certain amount of uncertainty exists of what lies ahead. Any journey has the potential for perils that need identification and hopefully preventive measures and control. Sometimes the endpoint comes prematurely and is unexpected. As with any process with a beginning and an end there is a time element built in. How long a journey lasts may be based on a fixed and fairly inflexible schedule or could be left indefinite. However, inevitably a destination will be reached at some point marking the end of the journey. Once having embarked on a journey the traveler will be left with a heightened level of experiential knowledge.

Pregnancy is not an illness but a developmental process. Throughout pregnancy, both the mother and the fetus journey together yet undergo their own individual dramatic process of growth and change. Experiencing my own journey of pregnancy combined with sharing the childbearing experiences of women who I have come to know both professionally and personally provided the foundations for this study.

I knew I was pregnant. It is hard to quantify how I knew but I did. It was the unrelenting heartburn that verified my intuitive knowing of my being pregnant. Suddenly it seemed the world was pregnant with me. I remember thinking where did all these pregnant women come from. Everyone seems to be having a baby. I attended prenatal classes to gain the information I needed to be prepared for what lies ahead. But I never really felt ready with total certainty for what the future held.

I remember undergoing a glucose tolerance-screening test late in my second trimester. I obediently drank the thick sugary liquid in the waiting room. It was horrid to taste but I felt it was important to ensure that everything was all right. I worried waiting for the results from the blood test. They came back normal, which filled me with guarded relief. I had passed the test but was everything really OK with my baby? How can I know with certainty?

I was eight weeks pregnant with my first child when we decided to go to Disneyland over the Christmas holidays. I wasn't wearing maternity clothes yet and had kept my pregnancy concealed to the outside world. I wasn't ready to tell anyone.

What if I miscarried? The amusement rides have always been a passion for me until now. The signs at the entrance gate of each ride seemingly call out to me to take heed. If you want to go on this ride go right ahead but you are taking a great risk for you and your baby. Remember you are pregnant and caution is required. I passed on by.

The ultrasounds were routine my doctor said and needed to check the size of my baby. I remember lying on my back staring at the ceiling tiles above me as the technician made the necessary preparations for the ultrasound. My stomach was exposed, somewhat rounded and full of life. A tiny life that up until now has stayed hidden from others was about to be revealed. My bladder was on overdrive, painfully trying to hold the many glasses of water that I had drank earlier that morning to be prepared. As I waited to see my baby for the first time my thoughts were split in two directions, one very practical "I need to get to a washroom!" and the other pensive "I wonder what I will see? I know that I haven't gained much weight so far. When I weighed myself at work my co-workers would comment with discouraging looks about how little weight I had gained. I hope everything is OK." The technician applied the gel and with the probe smears it all over my stomach. It was cold, gelatinous and sticky. My bladder protested. Hold on, it will soon be over I told myself.

Grayish, black and white images that lie far beneath my skin presented themselves on the screen overhead. I strained to focus as the probe circles round and round trying to capture something. How long is this supposed to take? My bladder was bursting. Finally the technician broke the silence, pointed out my daughter to me and stated, "There's the baby." Amazingly evident although not outwardly. A head, an arm, legs, a spine, a heart, and a stomach. Could she see me? Feel me? Hi baby I whisper, I'm your mom. Are you OK? This is actually happening and there's no turning back.

During my third pregnancy my doctor informed me of my eligibility to have an amniocentesis. I am a nurse and knew the statistics around advanced maternal age and the associated risks for the baby. Ok. So I'm thirty-five I thought. I have already had two healthy babies so why would this child and pregnancy be any

different. I told the doctor no. My decision not to have the test done was based on my thoughts of not being at risk. For me it was not taking the risk of inadvertently loosing a normal pregnancy. But a small part of me questioned my decision until I saw my son. Was I taking a risk? Was I at risk? What could I do about it anyway?

The baby moves. I feel my bladder once again being attacked. My coffee mug resting on my stomach is jolted and its contents spill on my dress. I am reminded that I am never alone on this journey. I rub my stomach and talk to its rounded presence and the being within. I waited for the delivery and hoped the journey would end well for us both.

I push one last time and feel my body open up as I wait for my child's first cry of protest as she enters the outside world. Our journey together has ended and the hard work getting there was suddenly a distant memory. Let me savor these timeless moments with my newborn. I am aware that there were many joys and uncertainties ahead. Am I ready?

This work evolved from my interest to further my understanding of pregnancy as it unfolds for women who face childbearing within today's highly technological world. As I listened to the stories of pregnant women who discovered they had developed gestational diabetes mellitus and an "at risk" pregnancy I saw a resemblance in how they perceived their pregnancy experience to the concept of embarking on a journey. It was the particulars of these women's pregnancy journey that I wanted to uncover and understand more fully. What can we learn from their pregnancy experience?

CHAPTER TWO

The Question

...a person who seeks to understand must question what lies behind what is said. (Gadamer, 1982, p.333).

Our questions reflect what we don't know about certain phenomena and what we seek to know and understand about our world. When our experiences conflict or no longer fit with our pre-conceived assumptions our reactions may include questioning to achieve a better understanding of the phenomenon. As Gadamer (1982) points out "a question comes to us, that it arises or presents itself, ... we can no longer avoid it and persist in our accustomed opinion." (p.329,330). Questions in the pursuit of understanding generate knowledge that is contextually based and developed through a reflective process. A search for in-depth understanding of an experience requires the acknowledgement that in our questioning there is no separation between the knowledge of the lived experience and the meaning of the lived experience (Bergum, 1989).

Through my clinical practice as a maternal-child nurse and my personal pregnancy experiences I have come to query the increasing level of medical surveillance and intervention associated with the care of childbearing women and their families. Questions regarding women's experience of a pregnancy that is judged by external means as being at risk bring this particular situation into the "open" for us as health care providers to understand. To fully understand phenomena we need to question and in our questioning "remain open to all possibilities"(p. 266) and interpretations (Gadamer, 1982). Asking questions encourages open dialogue where our answers maintain a certain degree of uncertainty. Gadamer contends that the openness of our questions implies that our answers remain indefinite. Through acknowledging the ambiguity of our questioning the phenomenon of interest remains in a state of indeterminacy, which leads to further questioning and deeper understanding. To enhance understanding Benner (1994) stresses the significance of establishing a sense of openness between people that uncovers similarities and

differences in a pursuit of "culturally grounded meanings" (p.104). I, as researcher, need to be attentive of my own assumptions about pregnant women's experiences and throughout my work remain open to being challenged, altered and transformed throughout the research process.

The intent of my question, "what is the meaning of being 'at risk' in pregnancy?" is to gain an indepth understanding of what it is like for women to experience a pregnancy that is, as a result of a blood glucose tolerance test, considered to put themselves and their unborn baby at risk. Gestational diabetes mellitus (GDM) manifests itself during the latter part of pregnancy and transforms what has generally been an uneventful pregnancy with no identified risk for a woman into one that is deemed to be at risk. GDM is usually detected by performing a routine blood glucose-screening test during the second trimester of pregnancy. However the clinical significance of GDM in terms of its level of risk and subsequent impact on maternal and neonatal outcomes remains debatable (Canadian Task Force on Preventive Health Care, 1994, 2001). The unresolved controversy surrounding prenatal blood glucose screening and treatment regimes for GDM perpetuates the lack of consensus within the medical community and may result in a state of confusion for pregnant women. What are the meanings inherent to women's experience of a pregnancy that is suddenly considered at risk? How does encountering potential complication during pregnancy fit with a pregnant woman's lived experience of a pregnancy that has been not considered at risk? What are women's thoughts and feelings about having an at risk pregnancy experience? What are the underlying themes that exemplify the thoughts and feelings of risk associated with having gestational diabetes?

Sandelowski and Perry-Black (1994) describe pregnancy as an event that is socially constructed and biomedically verified through diagnostic tests. They suggest the use of technology in childbearing has objectified a woman's pregnancy experience by "transforming the fetus into an object of inquiry." (p. 609). A woman's decision to undergo prenatal diagnostic testing involves knowing and not knowing the well-being of the pregnancy, the self and the fetus. Although a negative prenatal diagnostic test result may provide a woman with a sense of relief, a positive prenatal

diagnosis may heighten her uncertainties. Identifying any potential or real risks to the mother and her fetus interrupts the assumption of normality.

Being a mother was a role that I had considered for myself since early childhood. I imagined myself someday being a mother of five, two girls and three boys. That someday came in my late twenties when I discovered I was pregnant with my first child. I remember when my husband and I decided that the timing was right to have a child. My thoughts were *"I'm not getting any younger. My biological clock is ticking away at a very fast pace."*

Questions for this study began to materialize during my three pregnancy experiences. I was told that age 29 was old to be starting a family. The medical community defines women like me as "elderly primips". But what does that mean? Having never been pregnant before, I knew little about my ability to sustain a normal pregnancy and I was advised to have an ultrasound to see how things were progressing. Who am I to argue I thought. Besides I want to know that everything is all right. But then why wouldn't it be because I felt fine.

It is interesting when I reflect upon my initial visit to the doctor's office to receive medical confirmation of my first pregnancy. I sensed deep down that I was pregnant. It was more than the obvious evidence of my missed period. I just knew. I was apprehensive waiting for the verification of something that intuitively I felt had already happened. But was I really pregnant? I never really questioned my need to seek professional validation of my pregnancy. The receptionist said congratulations in the waiting room that, at the time seemed directed not only to me but also to all those within earshot. I saw the congratulatory smiles on the strangers' faces, people who moments earlier were oblivious of my existence. I'm going to have a baby I thought as I left the office. Do I look different to others I wondered as I walked to my car? Should I look any different? Can people tell that I'm pregnant? Does it matter if they do? My first experience with pregnancy and motherhood began that afternoon. As illustrated in a poem I pondered on the life that lay deep within my body.

Magnificat

Now the fingers and toes are formed,
the doctor says.
Nothing to worry about.
Nothing to worry about.

I will carry my baby to the mountain
I will bare it to the moon, let the wolves howl
I will wear it forever
I will hold it up every morning in my ten fingers
Crowing to wake the world.

This flutter that comes with me everywhere
is it my fear
or is it your jointed fingers
is it your feet

You are growing yourself
out of nothing
there's nothing
at last I can do.
I stop doing: you are
Miles off in the dark
my dark
you head for dry land,

naked, safe
in salt waters.
Tides lap you.
Your breathing
Makes me an ark

Author: Chana Bloch, *The spirit of pregnancy: An interactive anthology for your journey to motherhood*

The bodily changes that were occurring inside my body initially remained hidden to the outside world. I alone could uncover my secret by telling others about my pregnancy. Once my pregnancy was revealed either by my own declaration or from my obvious expanding stomach and breasts, my relations with others changed.

Total strangers would inquire about my welfare and touch my stomach as if they had some claim to the contents within. I began to notice the many pregnant women around me wondering where did they all come from. Have they always been there?

Throughout my three pregnancies I obediently underwent various recommended prenatal tests, such as, ultrasound, non-stress test and blood glucose screening, to determine the well being of my self, my unborn child, and my pregnancy, and to minimize uncertainties. I felt that my compliance to such actions was expected and the responsible thing to do. When I was pregnant with my son I was informed that at my advanced age I was at risk for adverse neonatal outcomes, particularly fetal anomalies, and that an amniocentesis was advisable. I told myself that I had experienced two normal pregnancies and consequently this pregnancy should be no different. However, I questioned my reasoning. Although I declined the test to either confirm or refute the presence of certain anomalies in my child, the seed of my being "at risk" for an abnormal child had been planted. My thoughts about my self as a pregnant woman became tainted and my world suddenly seemed different. The idea of risk was ever present in my mind and once mentioned could not be easily retracted. When my son was born I noticed skin tags on the one side of his face and beside his ears. The pediatrician told me these extra pieces of skin around a baby's face are sometimes associated with certain congenital syndromes and suggested further investigation. I remember thinking maybe I had been at risk but what can I do about it now?

My professional experiences working with childbearing women and their families stimulated further questioning about the decisions pregnant women make regarding prenatal care and diagnostic testing. Various tools are used to assess, diagnose and monitor fetal status. The value of these medical practices is not to be overlooked or undermined. Conducting prenatal diagnostic tests, such as blood glucose screening, amniocentesis, chorionic villi testing and ultrasonography facilitate the identification of women who are at risk for some adverse maternal or neonatal outcome and the subsequent implementation of needed interventions. Although technology has its purpose in reproductive care, questions arise whether

they meet the needs of the pregnant woman or pose a disadvantage to the woman's well-being.

In our research of women with severe nausea and vomiting in pregnancy, a model emerged that described a process through which the internal environment of affected women changed dramatically and caused them to withdraw and feel loss of control, alone, isolated and trapped in their experience (O'Brien, Evans, & White-MacDonald, 2002). These women's stories illustrated for me the complexity of their pregnancy experience. I began to question how we could be sensitive to the individual needs of these women. What does it mean to lose control of self and feel isolated in your childbearing experience? I found myself once again seeking an understanding of the medicalization of pregnancy and its affect on women and their families. Although the women in our earlier study were symptomatic and at risk for adverse outcomes, I wondered about the childbearing experience of women who may encounter a potential physical complication or risk during their pregnancy but who remain asymptomatic.

Risk is an integral part of living and most women are labeled to be at a certain level of risk at some point in their pregnancy. The term risk is used to draw attention to the potential or real threats to the wellbeing of the pregnancy, the mother and the unborn child. The screening tests to determine a woman's level of risk for abnormality set a precedent and give justification for continued surveillance of the woman throughout the pregnancy process. As a practicing nurse, I have used screening tests to measure the relative risk of childbearing women. But what does assigning a number to depict a woman's risk status during pregnancy really mean to a woman? I have often wondered what undue stress, anxiety, and feelings of uncertainty have been created for these women and their families. The concept of risk is value-laden and the assignment of having an "at risk" pregnancy can result in undue proliferation of tests that have dubious benefit and possible harm (Saxell, 2000).

Kaufert and O'Neill (1993) assert that the term "risk" is more than a statistic and when used becomes "an emotional issue, a matter of moral behavior" (p.33). The knowledge that she is now diabetic and that she and her fetus are at "risk" for adverse

outcomes may influence a woman's psychological status, management of her pregnancy and her perception of self and her fetus. What was once considered a normal process has now been elevated to a different status. The glucose intolerance that accompanies gestational diabetes is usually mild and affected women's pregnancies are asymptomatic. The diagnosis of gestational diabetes through a routine blood glucose test often comes as a shock for women who up until this point have been experiencing a "normal" pregnancy. Women's experience of their childbearing process that is considered at risk and their perception of being at risk could have an impact on their level of comfort and well-being.

When a pregnancy is classified as high-risk, the normal psychological processes of pregnancy are modified (Stainton, MacNeil, & Harvey, 1992a). The meanings that women ascribe to themselves and their experiences are products of their specific social situations. Women who encounter a complication in their pregnancy need to redefine themselves to fit their current situation. Many uncertainties and unanswered questions arise for these women. What is happening to me and why? Will my fetus and I make it through the pregnancy unscathed? What actions do I need to take to ensure our safety?

The presence of the term, risk, in the childbearing discourse places women under continual scrutiny of others and potential into adversarial relationships. Once revealed to the external world a pregnancy is no longer private, as it becomes part of the public domain. Women talk about being asked personal questions about their pregnancy by strangers. People, fascinated by the pregnant body, think it is their right to reach out and touch the swollen pregnant body. It is as if the woman is "divested of ownership of her body" (Balsamo, 1999, p. 231). She ceases to be an individual with rights to privacy and becomes an object to be examined and controlled. Through the use of technology, the unborn being lying deep within her body gains notoriety status. The body of the pregnant woman becomes deconstructed into its significant parts, namely the uterus, pelvis, and breasts.

By the second trimester, the pregnant body is physically obvious to outsiders. The woman is wearing maternity clothes and her enlarged abdomen is evidence to others that she is pregnant. However the mother still experiences a connection with

her body and the unborn that is unique and private to her. This bodily relation is an internal one that cannot be experienced by other people. Modern reproductive technology through perinatal tests establishes new relationships, whereby the fetus now has a definite connection to the outside world. Through the use of reproductive technology, the fertilized egg and the unborn have become new entities, revealed for public scrutiny. As Duden (1993) states the "public" fetus emerges and takes priority. The mother acquires knowledge from external sources about herself and her fetus that previously lay hidden and unknown.

From my professional and personal experiences I concluded that pregnancy and childbirth have evolved to be publicly a defined event while simultaneously remaining private and personal experiences for pregnant women. From a public standpoint recognition is given to the fetus as a separate entity rather than part of an intimate connected relationship with the mother. In this view a pregnant woman may be considered a threat to the well-being of her fetus, who as a consequence, is in need of societal protection. For example, a woman who declines perinatal diagnostic tests may be considered irresponsible and abandoning her moral obligation towards her fetus. A woman who chooses a home birth over a hospital delivery might be regarded as denying her fetus access to optimum care and potentially placing it in jeopardy. Societal, cultural and institutional beliefs and norms regarding childbearing women and their families may alienate a woman from her pregnancy experience and her fetus. Moral-ethical decision-making dilemmas can arise for pregnant women from pressures exerted by political and community groups and family and friends for women to produce children who contribute to society. In his book, *Midwives*, Bohjalian (1997) depicts the antagonism and hostility that is directed by traditionalists towards women and families who favor unconventional childbearing practices.

I have attempted through this work to illuminate the experience of pregnant women who develop gestational diabetes. In the first two chapters I raise my questions that have emerged from my own involvement both personally and professionally with present health care services directed towards childbearing women. I specifically focused on gestational diabetes, a pregnancy experience that is

determined through blood glucose screening and considered to be a risk for the mother and the fetus. Accompanying the label of risk in pregnancy is a heightened need for external control and surveillance of the pregnant woman and subsequent maternal feelings of anxiety and uncertainty.

In chapter three I discuss the nature of interpretative inquiry and feminist methodology in terms of their contribution to deepening our understanding of this phenomenon. The current controversy that is prevalent within the medical community about the significance of gestational diabetes and its management is discussed in chapter four. In the final chapters I address the question of what is like to experience an "at risk" pregnancy through conveying the storied experiences of a group of women who shared their experience of gestational diabetes with me. The emergent themes: living a controlled pregnancy, balancing, being a responsible mother, and being transformed are described separately but are intertwined and thus part of the whole pregnancy experience of these women.

CHAPTER THREE

Understanding the diabetic pregnancy experience

We are in part living in a world the constituents of which we can discover, classify, and act upon by rational, scientific, deliberately planned methods; but in part we are submerged in a medium that, precisely to the degree to which we inevitably take it for granted as part of ourselves, we do not and cannot observe from outside; cannot identify, measure, and seek to manipulate; cannot even be wholly aware of, inasmuch as it enters too intimately into our experience, is itself too closely interwoven with all that we are and do to be lifted out of the flow and observed with scientific detachment, as an object (Isaiah Berlin, 1978, p.71).

The person with understanding does not know and judge as one who stands apart and unaffected but rather as one united by specific bond with the other (Gadamer, 1976).

Women's pregnancy experiences are a legitimate source of knowledge and the validity of their perceptions should be recognized. In their work, *Women's Ways of Knowing,* Field-Belensky, McVicker-Clinchy, Rule-Goldberger, and Mattuck-Tarule (1986) differentiate between the two concepts, understanding and received knowledge. They suggest understanding is intimate and denotes equality and connection between the inquiring self and the inquired object. In contrast received knowledge implies inequality and separation with supremacy of the inquiring self over the inquired object.

Understanding entails "connected knowing and builds upon the subjectivists' conviction that the most trustworthy knowledge comes from the personal experiences rather than the pronouncements of authorities" (Field-Belensky et al., 1986, p. 112). Women gain personal knowledge of their pregnancy experience from a subjective, internal stance while health professionals heed an objective external perspective of women's pregnancy experiences. The personal knowledge that women acquire about their subjective self during their pregnancy is unseen and not readily evident to health care professionals. The meanings attached to an "at risk" pregnancy experience by women and health professionals can differ and result in divergent expectations and caring practices. Although both health professionals and pregnant women seek the

same outcome, a safe birth and a healthy baby and mother, conflict may arise regarding the means to that end.

It was with these presuppositions that I came to conduct this research. I sought to uncover the meaning of women's pregnancy experiences and capture the complexity of their situation. I wanted to describe from women's frame of reference, the experience of being considered at risk as a consequence of developing diabetes during a pregnancy, what it means in their everyday lives and the impact that this pregnancy experience has on their comfort and well-being during pregnancy and birth. To guide my research I asked: What is it like for pregnant women to encounter and be treated for gestational diabetes? What does the experience of having gestational diabetes mean to pregnant women? What is the meaning of being "at risk" in pregnancy? What is like to experience a pregnancy "at risk"?

To address these questions, I sought an approach which could (a) reveal women's personal knowledge of experiencing a pregnancy complicated with gestational diabetes, (b) illuminate the meaning this experience has for women, (c) uncover the impact of medical surveillance on the pregnancy experience, and (d) enrich our understanding of their perinatal comfort needs. A human science approach expands epistemological questioning to include the concepts of the knowable and inexplicable, that is, " ... to understand the true nature of things and their relations to each other, ... is to see past mere things and to gain access to the world of the in-between and the beyond" (Silva, Sorell, & Sorell, 1995, p.5). The philosophic perspective from which this study stems is the hermeneutic phenomenology tradition. Using an interpretative approach phenomena are investigated by staying grounded in the lived experience. Generating explanatory theoretical formulations or testing hypotheses about "at risk" pregnancies was not my intent.

Plager (1994) suggests our daily actions are so socially and culturally embedded in familiarity that we lose sight of our being or existence. The meaning of our everyday experiences is grounded in context and revealed through in-depth descriptions of human phenomena, that is "human actions, behaviors, and experiences as we meet them in the life world" (Van Manen, 1990, p. 19). The life world refers to the everyday life that a person experiences. An in-depth view into the implicit nature

of human experiences represents a process where one comes to understand a phenomenon in a new way. As proposed by Gadamer (1976) a hermeneutic inquiry utilizes a process that mediates the familiar and the unfamiliar aspects of human experiences.

Hermeneutic phenomenology is recognized as the science and art of interpretation (Allen & Jensen, 1990; Thompson, 1990; Weinsheimer, 1991; Appleton & King, 1997). Hermeneutics derives from the Greek words, *hermeneueuein,* "to interpret" and *hermeneia,* "interpretation". Both words are associated with the Greek deity, Hermes who was responsible for changing the unknowable into a form that was understandable to human beings. His task was accomplished through the use of language and the written word. Hermeneutics involves uncovering what is hidden to allow more complete or different understandings to emerge (Geanellos, 1998). Phenomenology is defined as the description of the lived experience and hermeneutics involves the understanding and interpretation of the lived experience in the context of everyday life. The inquiry tradition of description and interpretation to explore human phenomena has its foundations in such works as Merleau-Ponty, Husserl, Heidegger, and Gadamer. Merleau-Ponty (1962) states phenomenology offers "an account of space, time and the world as we live them. It tries to give a direct description of our experience as it is" (p. vii). His philosophical works abandoned the traditional notions of subject and object dualism and looked at intersubjectivity, namely the relations with others (Moran, 2000).

Van Manen (1984) states phenomenology offers a deeper understanding of the nature and meaning of the everyday world as we immediately experience it rather than as we conceptualize, categorize, or theorize about it. An understanding of human phenomena is generated by "drawing from participants a vivid picture of their lived experience, complete with the richness of detail and context that shape the experience" (Sorrell & Redmond, 1995, p. 120). This method of inquiry reflects the realm of human lived experience rather than the notion of causality. The outcomes of hermeneutic phenomenology are descriptive and transformative rather being explanatory and predictive (Vanderzalm & Bergum, 2000). A new understanding is

formed that will uncover an interest, illuminate a phenomenon or sensitize others who read the research findings (Koch, 1999). The purpose of such inquiry then is to attain a deeper understanding of a person's "life-world" through rich description and interpretation. Since I sought to understand the intricacies of these women's pregnancy experiences from their perspective, hermeneutic phenomenology presented itself as a suitable approach for my research.

The conception of modern phenomenology is often attributed to the work of Husserl, a German philosopher and mathematician from the earlier part of the twentieth century. Husserl supported a logical, reductionistic method to understand the experience of human consciousness. According to Husserl human consciousness creates what we know about our life-world. He contends that the human mind is intentional and directed towards objects that present themselves in the everyday world. This phenomenological approach conceptualizes people as detached beings existing in a world of "pre-existing" objects and perpetuates the Cartesian notion of a mind-body split. It implies disembodiment with the thinking individual remaining separate from others in the world.

Husserlian phenomenology is concerned with universality and absolutes (Walters, 1995). Husserl alleged that human experiences have certain eidetic structures or universal, central features about the world that are made evident through our conscious awareness (Omery, & Mack, 1995). The lived experience or one's "life-world" and its associated meanings can be examined and described in terms of essences (Koch, 1999). Emphasis is on the description of primordial phenomenon and gaining self-awareness of the world prior to making any judgments or assumptions. Husserl spoke of returning to the things themselves through "bracketing" or "suspending" one's pre-understandings or pre-suppositions about the phenomenon of interest.

For this study I abandoned the Husserlian study of human consciousness as a method for knowing and sought one that focused on questions of experiencing one's being in the world. The experience of pregnancy is one of embodiment and I needed an interpretative approach that would capture the strong contextual and historical aspects of a woman's pregnancy. The meaning of women's pregnancy experience is

grounded in rather than separate from their lived world. I felt a phenomenological approach that is associated with the positivist position and reductive process of Husserlian phenomenology was incongruent with women's ways of knowing and my endeavor to gain an in-depth understanding of pregnant women's experience of having gestational diabetes.

Heideggerian-Gadamerian hermeneutic phenomenology

My research is based on the phenomenology as described by Martin Heidegger and the philosophic hermeneutics of Hans Georg Gadamer. In Heideggerian-Gadamerian hermeneutic phenomenology three themes are present 1) the inherent creativity of interpretation, 2) the importance of language in human understanding, and 3) the interaction between part and whole in the interpretative process (Smith, 1994).

A major aspect of Heideggerian-Gadamer hermeneutic phenomenology is the rejection of Cartesian subject-object dualism. Phenomenology grounded in the Heideggerian-Gadamer tradition represents a shift from an epistemological emphasis on an understanding of essences and the seeking of universal truths to an existential-ontological understanding of a person's "being-in-the-world". The term, "being-in-the-world" refers to the notion that knowledge of our everyday existence is intersubjective, temporal and relational rather than objective, static and non-relational. A person comes to understand and gains meaning of the personal lived experience through establishing a dialectic relationship within the life-world. Merleau-Ponty (1962) states,

> All my knowledge of the world, even scientific knowledge, is gained from my particular point of view, or from some experience of the world without which the symbols of science would be meaningless. The whole universe of science is built upon the world as directly experienced, and if we want to subject science itself to rigorous scrutiny and arrive at a precise assessment of its meaning and scope, we must begin by awakening the basic experience of the world of which science is the second-order expression. (p. viii).

This view suggests there are no separate and distinct objective and subjective worlds but rather only the world as experienced by the individual. Multiple truths about reality are generated from which scientific knowledge is interpreted.

Heidegger, a student of Husserl's, subscribed to an ontological position that caused him to challenge Husserl's idea that meaning represents an independent reality and that knowledge is generated from the standpoint of a subject-object split (Koch, 1995). Interpretative researchers adopting the tenets of Heideggerian phenomenology seek an understanding of our experiencing the world, that is, our being in the world rather than describing the world. Human existence according to Heidegger does not remain detached as a disconnected entity in the world. Understanding human experience is rooted in the practical nature of the life world and cannot be approached directly (Moran, 2000). A person's lived experience is part of his being-in-the-world and cannot be separated out, as the meanings attached to that experience are part of that person's being. According to Heidegger to understand the phenomenon of human lived experience requires reflection on and interpretation of the life experience. The description of what and how the person says something about a particular phenomenon is not of primary significance. It is the meaning of what is said about the lived experience that is salient.

Phenomenology emphasizes intersubjectivity as the mode through which meaning is established (Thompson, 1990). Van Manen (1994) characterizes phenomenology as intersubjective in that it involves the development of a dialogic relation between the researcher and the participant. Intersubjectivity locates the unit of analysis and interpretation in the space created between the person and their world or between the participant and the researcher. Pierson (1999) suggests that an intersubjective process permeates the research process and can be conceptualized as an engaged relationship between the researcher and the research participant.

Heideggarian phenomenology is concerned with the shared experience and interpretation of the shared experience that exists between the self and other. Kvale (1996) suggests that knowledge generated by qualitative interviews exist in the relationship that exists between the person and the world rather than being only from external sources. I can pose the question "what is it like to have gestational

diabetes?" but in-depth understanding emerges from a merger of the interpretations of both the women's storied experiences of the phenomenon and my own lived experience. To describe the process of understanding Heidegger speaks of a back and forth movement between the phenomenon of interest and the researcher. The knowing-subject and the interpreted object-in-the-world are seen as co-participants in the world together rather than as remaining detached beings (Thompson, 1990; Koch, 1995; Walters, 1995; Annells, 1996). Drew (1999) states our shared world is co-constituted by all of us. She suggests that we are reflective beings whose self-awareness permits us to expand our understanding of the world from the perspective of our situatedness within it. To experience a phenomenon, Drew states, implies having an active and creative relationship with the world and others. Similarly Annells (1996) describes understanding human existence as being participatory.

Hermeneutic inquiry emphasizes the historical, contextual and temporal nature of the human lived experience (Thompson, 1990). The lived experience includes a person's being-in-the world. A person's understanding of their lived experience is circumscribed by their values, history, language, culture and prejudices. The researcher and participants form a dialectic relationship to share common practices, skills, interpretations and everyday practical understanding. The concept of temporality was fundamental in Heideggerian phenomenology. Human existence occurs over time and the understanding of human phenomenon includes past, present and future aspects of a person's experience in the world. Heidegger contends that what we understand now about our present experiences in the world is largely dependent upon the meaning and interpretation of our previous lived experiences. Human beings come to experience life situations with a pre-understanding and interpretation and as such, understanding and interpretation cannot be achieved without reference to one's past, present and future (Smith, 1994; Koch, 1996). Interpretation then can only occur against the background of a person's beliefs, practices and past experiences.

Bracketing, an important element in Husserlian phenomenology was considered impossible to achieve in this study. With a hermeneutic phenomenological approach it is deemed unnecessary for me, as researcher, to

bracket out my own experiences or preconceptions of pregnancy and risk. My experiences, preconceptions and prejudices related to pregnancy and childbearing were an intricate part of this research as they enabled me to reflect, understand and make sense of the women's lived experience of gestational diabetes. It involves making conscious and explicit my own experiences and how they may influence my interpretation of others.

Gadamer, a student of Heidegger, further developed the "historicity" and "temporality" of human existence and introduced the concept of language to understanding lived experience. The language we use prescribes, predefines and prejudices the way in which we orient ourselves to our world (Thompson, 1990). For Gadamer all human understanding is linguistic and understanding of lived experiences can be only revealed, shared and illuminated through our language (Hekman, 1986). Language is the medium by which human beings understand their world. (Leonard, 1994; Boutain, 1999). Language is produced locally and the ease with which understanding occurs depends on social, historical and cultural proximity.

The aim in hermeneutic inquiry is not only to describe and understand the phenomenon but also to come to know it in a different manner and to open new possibilities (Koch, 1996). Gadamer's key constructs include the hermeneutic circle, dialogue and fusion of horizons. He borrowed the metaphor, hermeneutic circle, from Heidegger to describe understanding as a dialectal process between the parts and the whole. Participation in the hermeneutic circle, Gadamer maintains, is an "enriching endeavor of relating parts and the whole with the anticipation of completeness" (Bohman, 1991, p. 137) for those involved. Hermeneutics signifies an ongoing infinite process of understanding. As an interpretative researcher I am continually present with the women participants and their narratives by examining my prior understandings and presuppositions along with those of the women informants. I recognize that my knowledge level on and experience with pregnancy and childbearing, my questions, and the women responses help shape the ongoing interaction with the women participants. Gadamer used the term, dialogue, to depict the presence of openness in inquiry that is characterized by continual question and answer. In his work, *Truth and Method,* Gadamer (1982) described dialogue as, "…

the process of question and answer, giving and taking, talking at cross purposes and seeing each other's point, performs that communication of meaning which with respect to the written tradition, is the task of hermeneutics" (p.351). To reach an understanding with another person involves more than a one-sided process where each person only asserts a personal point of view. Understanding is achieved through the process of dialogue and is the result of a reciprocal relationship between parties. Knowledge generation is a social construction of reality and it is through dialogue that understanding can be achieved (Kvale, 1996). Active listening and openness characterize the dialogue that occurs between the inquirer and participant or between the text and interpreter (Koch, 1999). Meaning of the women's pregnancy experience was constructed through the active engagement between the women informants and myself. As I read, re-reread and reflected on the typed transcripts I continued dialogue with the written texts.

Gadamer's final construct, fusion of horizons is the means for interpretation and understanding to occur. He asserted that all understanding is interpretation and occurs within a certain horizon. Horizons include our perspectives and prejudices and are not exclusive but open to other horizons. They have boundaries that are set by the prejudices of the time but are always changing. Smith (1994) contends that understanding is only possible when in dialogue individuals bring about a fusion of their different horizons to achieve a new understanding that they both can hold in common. Through dialogue there is a fusion of horizons, a meeting of the contextual understanding of myself as researcher-interpreter and that of the pregnant woman who is the participant-interpreted. Neither party in the hermeneutic process abandons his or her initial horizon. Gadamer contends that understanding is "the elevation to a higher universality which overcomes not only one's own particularity but also that of the other person" (1976, p. xi).

Some explicit assumptions that underlie a hermeneutic phenomenological research approach are acknowledged and their application to my work recognized. First the existence of ***a priori*** theory as source of categories for conducting data analysis is rejected. "The aim is to understand how people experience the world pre-reflectively, without taxonomizing, classifying or abstracting it" (Van Manen, 1990,

p.9). Scientific knowledge is a rigorous process of discovering meanings and patterns that are rooted in and emerge from a person-world interrelationship.

Second, reality is not something that is external to one's being in the world, waiting to be discovered and apprehended, but it is to be co-constituted by the inquiring person and the world. Under this paradigm, reality is experiential rather than mental or material. Merleau-Ponty (1962) considers that human actions are a result of the dialectal relationship and interaction between a person and the environment. Human understanding is considered relational in that people create meaning of the world through their interactions with one another. In summary, reality is constructed contextually, linguistically, historically and culturally.

Third, one universal truth or reality that pertains to the correspondence criterion where one strives to represent or reproduce reality does not exist under an interpretative paradigm. The humanistic approach captured within phenomenology implies that every situation or experience is unique. There is a shift from seeking general knowledge towards achieving contextual knowledge or multiple realities. Hermeneutics has allegiance to the coherence criterion of truth described by Kvale (1996) and involves multiple interpretations for complex phenomena. In this study, the women participants' narratives or storied experiences reflect a coherence theory of truth in that I strive to produce findings that make sense and are plausible. Narratives having been created within the realm of a hermeneutic circle of interpretation can change, as they are retold. Searching for the one true account of lived experiences is irrelevant (Sandelowski, 1991).

Fourth, lived experience can be best understood by focusing on subjective human experience. As Kvale (1996) points out, phenomenology is concerned with the participants' perspectives of their world and strives to capture the diversity of their lived experience. Hermeneutic phenomenology is more than a superficial description of one's experience. It strives to understand the essential meaning that constitutes a person's lived experience. The structures that are described are contextually constructed through linguistic means. These structures are descriptions of shared experiences that are embedded in our relationship with the world and their meanings are revealed through an ongoing dialogue between individuals. My findings were

created as the research was conducted and involved ongoing conversation between my self and the women as well as my dialogue with the typed transcripts.

The purpose of interpretative inquiry is to create meanings of lived experiences by uncovering that which is incomplete, mystified or hidden (Geanellos, 1998). The structures of meanings embedded in a person's experience are illustrated through written texts and narratives. These detailed stories or narratives are exemplars of everyday practices and lived experiences (Wilson & Hutchinson, 1991). Interpretation is an attempt to create the meaning of lived experiences in an effort to construct different or deeper understanding of human phenomena. A good phenomenological text according to van Manen (1997) is one that makes the reader suddenly see something in a way that enriches our understanding of everyday life experience. Rather than describing the usual perception of a phenomenon it generates a new way of looking at the phenomena of interest. Allen (1994) states that the end product is not a mirror of reality that is absolute and unchanging, but an interpretation or new understanding of particular phenomena and is always open for further interpretation. Evocation refers to revealing the essence of one's lived experience that results in further dialogue in the form of questioning and answering. "Phenomenological texts aim to enchant, to turn mundaneness into transcendence and familiarity into strangeness" (van Manen, 1997, p. 8).

Ricouer (1981) states "the text must be able to decontextualize itself in such a way that it can be recontextualized in a new situation- as accomplished, precisely, through the act of reading" (p. 139). He considers the text is the medium, through which we understand ourselves and states,

> …to understand is to understand in front of the text. It is not a question of imposing upon the text our finite capacity of understanding, but of exposing ourselves to the text and receiving from it an enlarged self, which would be the proposed existence corresponding in the most suitable way to the world proposed (Ricouer, 1981, p. 143).

Feminism

Feminism, a research tradition that has grown from acknowledging women's existential experiences of "being in the world" has relevance to this study. A feminist

way of thinking involves methods and activities that generate an in-depth understanding of the everyday lived experiences of people. Schwandt (1994) describes a feminist standpoint as one that focuses on the manner in which women's experiences are socially constructed. The purpose of feminist standpoint research is to provide a methodology where women's perspectives of their everyday lived experiences is stressed and built upon. Campbell and Bunting (1991) suggest that unity and relatedness, emphasis on subjectivity, and contextual orientation depict feminist theory, all similar to the tenets of phenomenology. Phenomenology is harmonious with a form of feminist inquiry where "the uniqueness and the contextualized nature of women's experiences and interpretation" is emphasized (Hall & Stevens, 1991, p. 19).

Feminist post-structuralism offers a paradigm that focuses on the historical, social and political elements that are present in relationships (Doering, 1992). Important concepts from feminist theories that are applicable to studying the experiences of childbearing women include consciousness-raising, emancipation and change (Reinharz, 1992; Andrist, 1997). The actualization of these outcomes require commitment to a relationship between women, dialogue between self and women, and encouraging women to recognize their strengths, resources, and abilities to act. Van Manen (1990) states that phenomenological researchers strive for precision and exactness by aiming for interpretative descriptions that exact fullness and completeness of detail. Acknowledging the primacy and subjectivity of the woman's pregnancy experience is crucial to reflect the diversity and uniqueness from which these women perceived their world (Wuest, 1994).

Researching the diabetic pregnancy experience

To address the research question, the interpretative researcher selects techniques that will illuminate the nature of a person's lived experience and yield a deeper and newer understanding and meaning of that experience. For a phenomenological researcher, Bergum (1989) states the research process unfolds as a dialectic process between their interests in exploring the phenomenon and the actual activities involved in conducting the study. The researcher must remain open to

interpretative possibilities and the uncertainties that come with this type of design. The phenomenological researcher affects and is affected by the research process.

While I conversed with the women, read and reread the written texts in my journal I had written words and phrases from the transcripts that seemed important to me. I remember questioning why I selected these particular passages. What significance did they have to my personal experience during my own pregnancies? What meaning did they have to the unfolding women's stories? For example, my notes around the women's descriptions of the reactions of others towards gestational diabetes elicited further questions into the women's experience of being under constant surveillance by others. I wrote a note about my experience of being told by co-workers that I was not gaining much weight during my pregnancy. Although I valued their concern at the same time I resented their intrusion into my privacy. I also remember feeling a heightened concern and questioning my sense of well-being. My self-reflection throughout the data collection and analysis process kept me aware of the emerging thoughts I brought to the research.

Although I embraced the tenets of interpretative research and it's philosophical framework for my work I endured some uneasiness in the process. The lack of structure that is inherent in the more familiar quantitative designs was initially unsettling to me. Yet, I realized that to address my questions and to truly understand women's experience of gestational diabetes and pregnancy I needed to overcome my discomfort. As I furthered my readings on the interpretative approach I realized how closely the underlying principles fit with my view of nursing practice particularly when interacting with women. I felt a hermeneutic phenomenological approach would generate the type of knowledge needed to enhance the care of women with gestational diabetes. I recall how refreshing it was to venture outside my imaginary box and experience the freedom involved with this method of inquiry. I realized I had to undo the preconceptions that had confined my thinking, be open-minded and see where I was led in my research endeavors.

To uncover the meaning of living a pregnancy that is associated with gestational diabetes, I wanted to talk with pregnant women who were diagnosed with and being treated for the condition. Sampling was purposive to ensure each person

was chosen based on her pregnancy experience and her potential to edify aspects of this particular pregnancy experience. All women needed to be pregnant and currently treated for gestational diabetes at the time of initial contact and first interview. To access eligible women I contacted a diabetic outpatient clinic located within a large urban hospital and met with the diabetic nurse coordinator, the physician in charge of the clinic, and other staff members to present my research plans and answer any questions. Letters of invitation (see Appendix A) to participate in the study were sent to the diabetic nurse coordinator to give to all eligible women who attended the clinic. I personally went to the clinic each week to determine if any eligible women were attending the clinic any on particular day. I received support from the clinic staff who would inform me of any women meeting the study inclusion criteria and having clinic appointments. The staff gave me the appointment list of all potential women who were coming to the clinic. I presented my research plans to each eligible woman on an individual basis while they were attending the clinic. For those agreeing to participate, a consent form was signed (see Appendix B) and arrangements were made for an interview at a mutually agreed upon time and place.

I soon realized that the women showed no hesitation in conversing with me about their experience. All of the women who I approached agreed to participate except for two. These two women indicated that they were too busy to schedule time to talk with me. What happened next was of significance to me. They both proceeded to talk to me in the public waiting area about their pregnancy experiences leaving me wondering what I should do with this information. They had declined participation but at the same time began to reveal some of themselves to me. Similar experiences took place in other venues. Upon hearing about my research, one woman at a nursing conference that I attended approached me and began to tell me about her experience with diabetes when she had been pregnant with her fourth child ten years previously. I realized that these women had stories to tell and wanted to be heard. I felt that not taking heed of their stories places me in a position of censorship of which I had no right. To engage in interpretative research means to be intimately part of the process and to remain open to all possibilities that may lead to deeper understanding

of human phenomenon being explored. I needed to overcome my hesitancy to pay attention to what I was being told and instead begin to listen to their words.

I sought multiple means to gather information for my study. However, my main source lay with the conversations I had with the pregnant women who had gestational diabetes. I listened as the women told me about their experiences of having diabetes during pregnancy. Their storied accounts inevitably became a major part of the research by stimulating additional thoughts and questions. I used literary works, both professional and lay, to help me understand the language used concerning pregnancy, diabetes and its management. I remained cognizant of any recent developments regarding pregnancy, diabetes, and high-risk obstetrics published in the medical literature as well as in newspapers or written health education materials for the lay public. When I went to the local library or a bookstore I sought out materials about pregnancy and diabetes. Chat room discussion groups on the Internet provided comments from women about managing diabetes while pregnant. Twelve women individually discussed their pregnancy experiences with me on two separate occasions, once during pregnancy and again after their babies were born. Of these, ten women had gestational diabetes; one woman had Type I diabetes; and one woman had discovered that she had impaired blood glucose tolerance prior to conceiving.

The dialogue

In keeping with the elements of a dialogue, my meetings with each woman were considered conversations rather than structured interviews. The approach I used involved discussing the topic together rather than me directing specific questions about their experience. I attempted to approach the process as suggested by Bergum (1989), whereby each conversation had a focus "but it was not one-sided"(p. 61). A conversation implies a discussion between the participant and researcher where there is a sense of equality and reciprocity. Rubin and Rubin (1995) state that having a conversation is a congenial and cooperative experience where both parties work together to reach a shared goal of understanding. In a dialogue the participant and researcher are engaged and each party tries to share common experiences to understand each other's messages and to simultaneously reflect on their own views.

When I talked with each woman about her pregnancy experience we both became engaged in our conversation.

The conversations were kept informal within an atmosphere of openness. They all took place at a time and location convenient to the woman. Most of the conversations took place in the woman's home but one was conducted at the woman's workplace. I told each woman that I was interested in understanding what her pregnancy experience was like from her perspective. I began the conversations by discussing my interest in a woman's experience of encountering a complication in pregnancy that renders her and her baby as being "at risk". All the conversations were audiotaped and subsequently transcribed verbatim. I also collected demographic data to further describe my sample (see Appendix C).

I met with each woman twice, before they had their babies and once again six to eight weeks postpartum. This was an attempt to gain a holistic picture of their pregnancy experience over time. To start our discussion about the experience of gestational diabetes, I asked a general question: "Tell me about having gestational diabetes. What has this been like for you?" I used open-ended questions with the intent of focusing on the women's thoughts as well as facilitating her freedom of expression (see Appendix D).

Many of the women began to talk freely and openly with little need for direct verbal involvement or probing from myself. When a conversation needed prompting I would use nonverbal cues such as nodding my head or moving closer. Other times I would try to have them describe the situation more deeply by asking: "Can you give me an example of that?"

Our second meeting focused on the remainder of the pregnancy, labor and delivery and the women's experiences since her baby's birth. During these second interviews the babies were present for either part or all of the conversations. Both the mother and I tried to keep them content. Older siblings were present for three of these second interviews and were at times part of the conversation.

Sample characteristics

Twelve women who attended a diabetic outpatient clinic in a large urban teaching hospital agreed to meet with me and share their pregnancy experiences. The

women ranged in age from 23 to 38 years and all but one worked outside the home. Eleven women were married and one was in a common-law relationship. Although most were Caucasian, the women came from varying cultural, social and educational backgrounds. This was the first pregnancy for 4 of the women, the second for 5, and the third or more for 3. Five of the multiparous women were encountering diabetes for the first time. Two of the women's previous pregnancies had ended in miscarriage. One of the women was pregnant with her second child and had Type I diabetes. Another woman discovered that she had high blood glucose levels about six months before she became pregnant. Seven women had vaginal deliveries. All the babies were born healthy and at term with birth weights between 5 lb 14 oz and 9 lb 10 oz.

Analysis

The aim of an interpretative inquiry is to grasp the essential meaning of the phenomenon being studied. In hermeneutic phenomenology, data collection and data analysis occur simultaneously, rather than sequentially, to capture a sense of the whole structure of the phenomenon. Following my conversation with each woman I began a reflective process in an attempt to fully understand each woman's pregnancy experience. This process of intense reflection as described by Baker, Wuest, & Stern (1992) involved asking myself, "What is this woman trying to tell me about her experience? What does she talk about? What stories are being told? What words does she use to describe her experience?"

The use of reflective journaling helped me to monitor my thoughts that arose throughout the study. I kept a personal journal to document and describe my thoughts, impressions, experiences and observations immediately after each conversation. My journal also served as a place for me to write down my perceptions and reactions that were generated by my exposure to literary sources and discussions with others. Reflexivity involves focusing on " the researcher-participant relationship throughout data collection and analysis, pinpointing any mutual influences on the nature of responses" (Hall & Stevens, 1991, p. 21). Through my journaling more questions were formulated that related back to different aspects of the conversations I had with the women. As I continued my inquiry I began to focus on particular

aspects of these women's pregnancy experience. I re-visited the feminist literature to capture the essence of control and theories of the woman's body. I sought literature about risk-taking behaviors, high-risk pregnancy and prenatal testing and surveillance.

Immediately following my meeting with each woman I listened to each audiotape for clarity. A trained transcriptionist transcribed all the conversations. After the transcribing, I listened to the tapes and compared the voice recordings to the typed transcriptions to identify any inaccuracies, irregularities or omissions. As I listened and read I made notes about any overt occurrences, such as, laughter, silences, interruptions or changes in tone.

Data analysis in phenomenology is a reflective process and was consistent with the guidelines of thematic analysis. Thematic analysis as defined by Van Manen (1990) refers to the "process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work" (p.78) and facilitated my analysis for this study. He states that composing linguistic transformation is not a mechanical exercise but a very creative endeavor. According to Van Manen four existentials help to guide thematic analysis: lived body (corporeality), lived space (spatiality), lived time (temporality) and lived relations (relationality).

I used an approach that Kvale (1996) refers to as a dialogue with the text to uncover the embedded meanings in the typed transcripts. First I concentrated on what the woman's experience meant as a whole and before exploring its parts. That is, I read each typed transcript in its entirety to determine what was written before I focused on any particular components. Reading and trying to understand each typed transcript in its totality helped me gain a sense of the meaning embedded in the language used by the women to describe their pregnancy experience. As I continued to read and re-read each transcript I became immersed with the written text and questioned, "What is being said here? What does this word mean in terms of how she is describing her experience? What is she talking about here? What stories are being revealed in different portions of the typed conversations? My involvement was more than providing a description of these women's pregnancy experience and included

much creative thought. In my writing I become involved in self-reflection and espoused the aesthetic aspects of writing.

I wrote notes directly on the transcripts to capture my questioning and thoughts. This reflective writing generated more questions and guided my quest for a deeper interpretation of these women's experiences. Through this process, I was led to ask additional questions when talking with the women in subsequent meetings as aspects of the pregnancy experience began to unfold through my reading and rereading of the many transcripts.

Interpretation of the written text was used to enhance my understanding about these women's pregnancy experience. Through inductive reasoning I examined the words, sentences and paragraphs to search for all possible meanings of the pregnancy experience being described by the women. It is through examining parts of the storied experience that in-depth understanding of the whole pregnancy experience began to unfold. By moving back and forth between the parts and the whole of the written text a dialectal process emerged. Significant elements that captured the women's pregnancy experience were highlighted and synthesized into the women's stories. Each reading brought new insights that help to further my understanding and disclose the meaning underlying the diabetic pregnancy experience. I wrote and re-wrote the stories around the key elements that had emerged from what each woman shared in their conversations with me.

The women's stories allowed me to identify and transform key elements embedded within the text into themes. As the researcher detects the emerging themes, certain experiential themes recur in the various stories (Van Manen. 1990). For example, in the women descriptions of their pregnancy experience with gestational diabetes stories around issues of control and being controlled were revealed.

A summary of the collective themes is constructed from the women's stories. They are described in abstract form and serve as meanings that reflect the women's experience of gestational diabetes as told through their stories. Sandelowski (1995) suggests this strategy elicits the elements from the data that best preserve the context of the participants' experiences and maintain the connection between the pieces of

transcription with the total narrative. I chose specific quotes from the women's conversations that would contribute to a rich description of the storied experience.

Establishing rigor

Preserving the scientific integrity of any research study is crucial to ensure the value and justifiability of its findings. The interpretation and meaning of conventional evaluative criteria vary between a logical empirical paradigm and a phenomenological framework (Beck, 1994). Strict adherence to the traditional techniques to ensure scientific rigor in qualitative work threatens "to take us too far from the artfulness, versatility, and sensitivity to meaning and context that mark qualitative works of distinction." (Sandelowski, 1993, p.1). Validity in any research endeavor is acknowledged but researchers consider adherence to the dominant quantitative model categories of scientific rigor as problematic and irrelevant for qualitative work (Mishler, 1990; Van Manen, 1990; Maxwell, 1992; Kvale, 1995; Koch & Harrington, 1998).

Adhering to a feminist post-structural framework, Lather (1993) suggests a reconceptualization of validity that considers the politics of what is happening at the local practical level. She purports a validity that moves away from the correspondence criteria of truth to one that is "multiple, partial, endlessly deferred" (Lather, 1993, p.675). Lather's focus is on methodological rigor that elicits change and supports the rights of participants to be part of the research process. Drawing on Lather's work, I embarked on my research remaining open to the endless possibilities or "truths" that emerged through my conversations with the women and trying to prevent any tendency towards reductionism. I was accountable to the women's stories as told to me and in my interpretation to retell their storied experiences as distinct from my own.

Lincoln and Guba (1985) challenged the use of validity and reliability for addressing rigor in qualitative research and in their work, *"Naturalisitc Inquiry"*, proposed alternative terms for establishing scientific rigor. Their original model strives to establish some degree of scientific merit to qualitative research and calls for the evaluation of trustworthiness to determine the legitimacy of research findings.

Trustworthiness was determined by judging the research on the following criteria, truth- value, applicability, consistency, and neutrality.

Critics have questioned Lincoln and Guba's model in terms of its relevance to addressing rigor in qualitative work and suggest the terms reflect the positivistic paradigm (Van Manen, 1990; Bailey, 1996; Schwandt, 1996). Maxwell (1992) stipulates that directly applying the typologies developed for quantitative designs to qualitative research distorts the fundamental premise of the latter, namely the understanding of phenomenon. He suggests reformulating the categorization of validity in qualitative work to be congruent with the nature of truthfulness in qualitative inquiry. Validity in qualitative work "does not depend on features of the account itself, but in some way relate to those things that the account claims to be about." (Maxwell, 1992, p. 283). In her later work, Lincoln (1990) considers the term authenticity rather than trustworthiness as more suitable and reflective of the complexities inherent in the qualitative model.

Mishler (1990) redefines validation in interpretative research as "the process(es) through which we make claims for and evaluate the 'trustworthiness' of reported observations, interpretations, and generalizations" (p.419). He advocates the dismissal of the standard validity model and redefines validation as being a social construction of knowledge. For Mishler, the evaluation of trustworthiness is more than a technical undertaking but involves tacit understanding of a contextually grounded cultural and linguistic research practice.

Koch and Harrington (1998) similarly advocate for an expanded view of rigor that moves us beyond using a methodological approach evident in quantitative research. They suggest validation criteria can be developed within the research study through incorporating a reflexive account of the actual research process. Reflexivity, they claim is achieved by addressing the question, "what is going on?" throughout the entire research process. By remaining reflexive the researcher acknowledges both the personal and historical factors that have influence on the research process. Rose and Webb (1998) concur and suggest that in the hermeneutic tradition the researcher is an integral part of the research process that in turn demands a reflexive approach to establish rigor. In discussing data analysis for example they contend that rigor

involves demonstrating an understanding of decisions made and actions taken rather than strictly conforming to predetermined rules.

Validity pertaining to qualitative work has been associated with evaluating the integrity and dependability of the entire research process. To demonstrate justifiability of qualitative findings Morse (1989) states the rigor of the entire research process must be considered. Kvale (1995) refers to validity as an expression of craftsmanship with an emphasis on the quality of the research through monitoring, questioning, and theorizing about the phenomenon of interest. The final research project as a constructed tapestry that is plausible "when it is engaging and has an internal logic achieved by detailing every interpretative turn of its makers" (Koch & Harrington,1998, p. 889). The process of validation rather than validity is more appropriate states Bailey (1996) to determine the quality and scientific integrity of qualitative work. Validation according to Bailey includes a clearly outlined research methodology, data analysis, and presentation of findings.

It can be argued that any research endeavor requires evaluative criteria that are congruent with its underlying philosophical premise. A hermeneutic approach is contextual, historical and spatial and leads to understanding of meaning that is constituted through dialogue between the researcher and the participant. In interpretative inquiry one can never achieve epistemological certainty, as is the intent of empirical criteria for validity and reliability. The primary aim of this interpretative research is not restricted to valid descriptions of events, behaviors or objects but includes what these phenomena mean to the people engaged in or with them (Maxwell, 1992). Through interpretation one seeks to understand phenomenon from the emic perspective, that is, from the viewpoint of the participants.

Philosophical hermeneutics offers no new methods for conducting interpretative inquiry but seeks instead to describe and interpret what actually is taking place in the specific event (Gadamer, 1982). The standards for scientific inquiry for this study remained consistent with the naturalistic paradigm and congruent with the assumptions underlying interpretative inquiry. The criteria of reliability and validity were abandoned and trustworthiness and authenticity were used to determine its integrity.

Trustworthiness relates to the study's credibility. My task was to present the many realities of the women informants in a way that is believable and of value to others. It considers how well the participants' lived experiences have been represented. The cumulative knowledge is believable or is identified as lived-through experiences (Leininger, 1994). Interpretative researchers assert that scientific knowledge has merit if it is intersubjective and is recognized by other, i.e. through data analysis, my description of the women's experiences captures their lived experiences. A credible study would fit Van Manen's (1990) definition of a good study as one "that we can nod to, recognizing it as an experience that we have had or could have had" (p. 27). According to Hall and Stevens (1991) a credible feminist research report would produce faithful descriptions and interpretations of the women's pregnancy experiences. Research findings are considered credible if others recognize, understand and endorse the researcher's description and interpretations of the women's experience as their own. "The proof for you is in the things I have made... how they look to your mind's eye, whether they satisfy your sense of style and craftsmanship, whether you believe them, and whether they appeal to your heart" (Sandelowski, 1994, p. 61).

I continually found myself critiquing and reflecting upon the goals, questions, decisions, analysis and conclusions made throughout the research process. To demonstrate credibility throughout the process I used a reflective approach by keeping a journal to describe my on-going self-awareness, thoughts and feelings. This offered me a strategy to examine and be constantly aware of my values, assumptions, characteristics and motivations and to monitor how they may affect the research process. Consultation with my supervisor and committee members helped to verify the effectiveness and comprehensiveness of the data collection, data analysis and the logic surrounding decisions and arguments that were made. Throughout data analysis my conclusions were continuously verified by re-reading the transcripts and discussions with my dissertation supervisor.

I brought and reflected upon my own pre-understandings, personal history, assumptions and motivations to the research situation, which together can influence my interpretation of the women's stories. Bracketing is often considered a means for

addressing rigor in qualitative research. It is defined as the conscious effort of putting aside one's beliefs, remaining non-judgmental and neutral about what is being heard or seen and keeping open to what is being revealed (Streubert & Rinaldi-Carpenter, 1995). The process of illustrating researcher bias and ***a priori*** convictions enables these biases to be held in abeyance (Baker, Wuest, & Stern, 1992). The biases and assumptions explicated in this study come from my personal and professional experiences with pregnancy and childbearing.

There are arguments against the use of bracketing in interpretative inquiry. In her work on mothers, Bergum (1989) states, "she can't put herself outside the problem that I formulate " (p. 58). Presuppositions and preconceptions of the researcher are part of the research process and require reflexive thought. It is by bringing our pre-understandings to consciousness that we can facilitate understanding. The interpreter can examine the origin, adequacy and legitimacy of his or her pre-understandings in relation to the phenomenon of interest and textual interpretation (Geanallos, 1998). Our prejudices and pre-assumptions are part of our 'being-in-the-world' and consequently not something we can eliminate or bracket out (Koch, 1995). Both the researcher and the participants bring their prejudices, traditions and pre-understandings to the research process.

This study is based on the assumption that the researcher cannot remove or detach his or her views, preconceptions and prejudices. Throughout the research process, understanding of one's previous and present experiences is considered contextually and socially constructed. The research process evolves into a collaborative relationship that leads to "an understanding that is a fusion of the views of the researcher and the participants" (Haggman-Laitila, 1998, p.13). Journaling and self-reflection throughout the research process helped me to be aware of my thoughts and how they might affect the findings. What the women told me about their pregnancy experience challenged my own thoughts about childbearing.

A comprehensive methodological documentation in which all decisions can be identified, explicated and traced is required for an accurate assessment of a study's credibility (Lincoln & Guba, 1985; Sandelowski, 1986). Documentation of all methodological decisions and rationale were made in an attempt to substantiate the

trustworthiness of the study. All analysis, reflective insights and their outcomes were noted in writing. Field notes were kept during the interviews to record contextual data such as, description of the setting, nonverbal behaviors, activities of others present during the interviews, distractions, and interruptions.

Closely related to a study's trustworthiness is its authenticity. Manning (1997) states authenticity concerns the researcher-researched relationship, any power inequities, usefulness of the research findings and research conduct. To enhance the authenticity of this study informed consent was sought from all the participants. Manning also suggests that the researcher is accountable to the individuals who open up and share their experience. She states that authenticity is not the assurance that the interpretation is the right one but instead refers to representing those lived experiences in all their complexity.

Returning to the informants is considered part of the research process and necessary to confirm or recheck findings (Hall & Stevens, 1991; Leininger, 1994; Kvale, 1995; Bergum, 1997; Thorne, Reimer-Kirkham. & MacDonald-Emes, 1997). Some phenomenological researchers have questioned the usefulness for seeking validation of emerging themes by study participants in interpretative research (Sandelowski, 1993). The criticism is based on the premise that the experience of the interview process itself has an impact on the knowledge generated and to go back for verification suggests the existence of a universal truth. However, member checking was considered fitting in this study as a means to ensure that the emerging interpretation of the pregnancy experience remained true to the women's storied experiences. I considered the themes that together exemplified the experience of gestational diabetes were not a sole result of my interpretations of the women's experience but have been co-constructed with the women participants throughout the research process. My questioning whether my interpretations of the women's stories fairly reflected the women's lived experiences of gestational diabetes led to my going back to the participants for their feedback.

As Manning so eloquently points out, " to neglect member checking means that the researcher's voice is the only one assuming the authority to interpret and construct findings. This elitist stance is incongruent with a subjectivist epistemology"

(p. 102). Hall and Stevens (1991) suggest a study's credibility is enhanced when the findings stay faithful to the participants' experiences and are recognizable as their own. I felt accountable to the women recognizing the themes revealed the experience of gestational diabetes. I sought validation of the emerging themes by returning to some of the participants for confirmation of the emerging themes. I chose quotes from the conversations that would contribute to a rich description of the storied experience.

Ethical considerations

Ethical approval to conduct this study was obtained from the Health Research Ethics Board review committee of the Capital Health Authority. All participants were invited to participate in the study through a letter of invitation. At the time of initial contact the nature of study was explained to the woman and any questions were answered. Each participant was informed of her right to withdraw from the study or to refrain from answering any particular question during our conversations. She was told how to contact my supervisor and me. Each interview was conducted at a time and in a location that was convenient for the participants. Informed consent was obtained from each woman prior to conducting interviews.

The nature of this study presented other significant ethical issues that needed to be addressed. Pregnancy and birth is a highly personal event in any woman's life. The nature of phenomenological inquiry requires that both the researcher and the woman reflect on their experiences and face the complexities of an inter-subjective interaction. Being involved in phenomenological inquiry may produce powerful emotional responses on part of the women and the researcher. Disclosure of the personal self by these women may reveal unpleasantness, emotional trauma, stress, and vulnerability. I needed to be sensitive to the women's experiences as they were being told to me and aware of the intense emotions that might arise. None of the women indicated a need to withdraw. Many expressed how good it felt to talk to someone about their childbearing experience and their desire to have information available about what it was like to encounter diabetes and pregnancy.

The act of reflection intrinsic to this research can have a transformative effect on the researcher and the participants. The women through their involvement in the

study may change the way they view their pregnancy experience and heighten their self-awareness. The study does not end after the final conversation. As a phenomenological researcher my initial dialogue with these women continues as I reflect upon and write about their experiences.

Limitations

The results of this study are limited to my past experiences, both personal and professional, my prejudices, and my understanding of an "at risk" pregnancy. The research reflects my understanding of what is like to experience gestational diabetes but only from the perspective of the women who chose to share their experience with me. It is not possible for me to capture the whole understanding of the experience or to provide any inferences. The findings are limited to my ability to interpret and write about the women's storied experiences in addition to the other sources I sought out.

Gestational diabetes in general, current management issues and previous research is discussed in the next chapter. The women's storied experiences of gestational diabetes and pregnancy are presented in chapter five and the common themes depicted in these stories are described in chapter six.

CHAPTER FOUR

The gestational diabetes dilemma

A model of maternity care based on primary prevention of problems must use a comprehensive approach, both in its science and its philosophy (Enkin, 1994, p. 134).

The content covered in this chapter serves to provide relevant background information regarding current recommendations in caring for women who encounter pregnancy-induced diabetes. The literature reviewed for this study focused on the concept of risk in pregnancy, issues regarding screening, diagnosis and treatment for gestational diabetes, and psychological concerns associated with a pregnancy complicated with diabetes.

The label, "at risk" is a common and familiar term ascribed to many pregnant women. Merriam-Webster (1997) defines risk as "the possibility of loss or injury; a dangerous element or factor; to expose to hazard or danger or to incur the risk or danger of something" (p. 638). This definition fits is congruent with the medical model's perception of pregnancy as being a condition that has a strong element of potential danger or risk for the health and wellbeing of a mother and fetus. Attaching the term "at risk" to the childbearing period espouses a negative view that the pregnant body is in a constant state of possible peril. One can argue that the imposition of a risk category on all pregnant women makes them recipients of interventions to eliminate or reduce the perceived level of risk. Rather than being regarded as a natural event, birth associated with the use of a risk approach is considered a life-threatening situation requiring "surveillance, control, and intervention at any sign of deviation from the normal" (Enkin, 1994, p. 133).

A meaning of risk is diverse and dependent on whether that definition is based on an epidemiological, clinical or lay perspective (Kaufert & O'Neil, 1993). From an epidemiological standpoint, risk exists as a statistical artifact and refers to the absolute, relative and attributable risks for certain trends and outcomes. Rhodes (1997) contends that an epidemiological categorization of risk and risk behaviors is devoid of understanding a person's lived experience of risk. Home births, for

example, are considered by some to be unsafe in terms of the level of risk for maternal and neonatal morbidity and mortality as compared to hospital births. What is lacking in this argument is the woman's perception of what is "at risk" for her and her unborn child. Saxell (2000) suggests that the label "at risk" is only beneficial to expectant mothers if something can be done to decrease or eliminate any factor they believe is a risk to themselves and their fetus. Health care professionals use the findings of epidemiological work in their effort to minimize risk factors and avoid or prevent future suffering and adverse outcomes. In determining what is a pregnancy risk, health practitioners rely on epidemiological accounts to prioritize identified risk factors and to ascertain key maternal and neonatal outcomes.

Sherwin (1992) suggests that the medical community characterizes various bodily and mental events experienced by women as being pathological. Applying the notion of pregnancy as a disease to the childbearing period can lead to objectification and an overstated emphasis on the element of risk for pregnant women and their unborn infants. A pregnancy that is considered at risk constitutes grounds for direct medical intervention to alleviate or minimize any risks for the pregnant woman and her unborn child. The perceived value of minimizing risk in pregnancy warrants the introduction of innovative forms of reproductive technologies onto the childbearing process. Young (1984) states that a medical discourse on childbearing perpetuates the idea that a pregnancy does not belong to the woman herself. She suggests when pregnancy is viewed as an objective, observable process it becomes manifested by the women as a condition in which she must take extra care of herself and be cared for by others.

Risk is considered a socially constructed discourse. Individual risk perceptions are mediated by social norms of what risk means and what constitutes a risk. For example, Rhodes (1997) contends that it is social interactions rather than the individual person that play a crucial part in what is perceived as a risk behavior. He claims a dialectal relationship exists between how societal structures and norms construct risk for individuals in their lives and how these individuals respond. Throughout the prenatal period, a woman develops certain beliefs and perceptions about her pregnancy, her pending motherhood and her unborn child. The connotation

of being "at risk" is a subjective experience for pregnant women and their families. Frankenberg (1993) suggests that any discussion of what is a risk to an individual person is also connected to moral, social and political discourses. Pregnant women's perceptions of risk are also influenced by both the contexts in which they live and the structure and practices of the health care system (Atkinson & Facanha-Farias, 1995).

The medical definition of pregnancy risk is largely dependent upon objective measures that are based on women's medical status. Within the medical community risks are assumed discoverable, measurable and with expert knowledge and skill can be controlled, minimized and ultimately eliminated (Gabe, 1995). Medical attitudes regarding childbearing involve defining it as a process that requires a significant amount of specialized monitoring and interventions to reduce risks and to achieve optimum maternal and neonatal outcomes. Health care providers may regard risk in pregnancy as being determined by environmental factors. Women's definition of risk is culturally based and acquired through local knowledge and experience (Kaufert & O'Neil, 1993). Pregnant women's subjective perception of personal risk during pregnancy may be contrary to the formal biomedical model of risk that underlies traditional health care practice. In their descriptive study of 27 hospitalized pregnant women who were experiencing a high-risk pregnancy, Ford and Hodnett (1990) examined the effects of stress and social support on maternal adaptation. Their findings indicated that risk involved a subjective component that relates to the women's perception of the degree of danger for the baby. A woman's appraisal of her pregnancy risk is independent of and sometimes contrary to the assigned numerical value set by health professionals on her medical status.

Other researchers have explored the experience of women whose pregnancies were classified as high risk. In a longitudinal phenomenological study of 27 pregnant women in high risk perinatal situations, Stainton, MacNeil, and Harvey (1992b) concluded that being considered "at risk" had different meanings for the mothers and their caregivers and may lead to tension or conflict between the two parties. While the health professionals tended to focus on potential adverse maternal and neonatal outcomes and appropriate strategies to minimize risk, the women were concerned with the possibilities of positive outcomes and becoming a mother to their baby. The

researchers suggest that health professionals need to broaden their knowledge base by increasing their understanding of what is embedded or concealed in these mothers' lived experience of a high-risk pregnancy.

Heaman, Beaton, Gupton, and Sloan (1992) compared the childbirth expectations of hospitalized high-risk and non-hospitalized low-risk pregnant women during the third trimester of pregnancy and examined the influence of anxiety, risk status, and childbirth preparation on these expectations. The researchers found that the high-risk pregnant women had significantly less positive childbirth expectations than did the low-risk group. However the women's subjective perceptions of risk were measured after the women had been diagnosed as high-risk. Although the expectations concerning their pregnancy may have changed as a consequence of becoming high-risk, a cause-effect relationship could not be established from this study.

Using the naturalistic inquiry of grounded theory, McCain and Deatrick (1994) interviewed 21 women who experienced a high-risk pregnancy. The women expressed feelings of vulnerability, anxiety and inevitability of their pregnancy outcome. Feelings of lack of control, uncertainty and stress have been associated with many women experiencing high-risk pregnancies (Stainton et. al., 1992b; Clauson, 1996; Hatmaker & Kemp, 1988). There is an element of unpredictability with any pregnancy but this statement is valid for many life events. This unpredictability of pregnancy outcomes both for the self and the unborn child can be a source of anxiety and stress for any pregnant woman. Stress can originate from the conflict between the mother's felt capability of producing a healthy baby and her need to conform to the demands of others and societal norms (Tisdall, 1997).

The emotional effect of having a high-risk pregnancy has been examined to a limited extent in the literature cited. There remains a paucity of knowledge or in-depth understanding of what is the meaning of risk in pregnancy and what it is like to for a woman to experience a pregnancy that is labeled "at risk". To gain insight into the medical view regarding gestational diabetes there is a need to examine the issues pertaining to its diagnosis and management.

Gestational diabetes mellitus

Gestational diabetes mellitus (GDM) is characterized as a carbohydrate intolerance of variable severity with onset or first recognition during pregnancy (Avery & Rossi, 1994;Gabbe, Hill, Schmidt, & Schulkin, 1998; Garner, Okun, Keely, Wells, Perkins, Sylvain, & Belcher, 1997). This definition is broad, and includes diabetes that originates during pregnancy, diabetes that persists after delivery, and diabetes that was present pre-conceptually but went undiagnosed. GDM affects up to 14 percent of the general pregnant population (Jovanovic & Pettit, 2001). Variations in recommended screening criteria, the screening techniques used, and the specific population being studied contributes to the variability in the incidence of women diagnosed with GDM (i.e., between 0.15 to close to 40 percent) (Stephenson, 1993).

The primary purpose of a screening test is to identify a subgroup of a given population that is at risk for a given disorder rather than to diagnose a disease (Carr, 1998). The ultimate utility for any screening test is for the implementation of an effective intervention to achieve positive outcomes and to reduce morbidity and mortality rates in those affected. An effective screening tool needs to be sensitive, specific, and easily applied (Soares, Dornhorstt, & Beard, 1997). Meltzer & Coustan (1998) suggest the identification of women at risk for gestational diabetes has the potential for caregivers to implement preventive strategies such as changes in diet and activity levels in an effort to minimize the development of diabetes later in life.

The clinical significance of gestational diabetes in terms of its risk and subsequent impact on the mother and her infant remains a debatable issue. Goer (1996) contends that the diagnosis and treatment of any medical condition must: 1) pose a real or potential health risk; 2) accurately distinguish between those who have the condition and those that do not; 3) have effective treatment available, and; 4) show the benefits of diagnosis and treatment outweigh the risks. The diagnosis and management of gestational diabetes Goer argues fails to meet the above criteria and that there is little evidence that the present management of GDM is successful in terms of achieving optimal neonatal and maternal outcomes.

Two conflicting thoughts regarding blood glucose screening for gestational diabetes mellitus during pregnancy exist within the medical community. Some

clinicians endorse a universal approach and recommend blood glucose screening for all pregnant women while others advocate selective screening of pregnant women with known risk factors. Women, their families, and health professionals are entrapped in this debate and as a consequence face the dilemma of deciding whether or not to have blood glucose screening performed. The decision to undergo blood glucose screening results in confirming or refuting one's level of risk.

Certain risk factors or criteria are shown to be prevalent in the histories and clinical presentations of women who develop gestational diabetes mellitus during pregnancy. These risk factors include: 1) past reproductive events, such as delivery of a large infant (>4500g), unexplained fetal demise, congenital anomalies, premature birth, previous pregnancy with GDM; 2) a family history of Type II diabetes; 3) clinical characteristics, such as obesity, excessive weight gain, glycosuria, proteinuria, hypertension, maternal age of 30 years or over; and 4) ethnicity, namely, Hispanic, First Nation, Afro-American and Asian (Avery & Rossi, 1994; Carr, 1998; Greene, 1997; Helton, Ardnt, Kebede, & King, 1997).

In a longitudinal study of 824 women diagnosed with GDM risk factors, obstetrical complications and infant outcomes were evaluated (McMahon, Ananth, & Liston, 1998). The researchers found that maternal age, pre-pregnancy weight, previous spontaneous or induced abortions, past history of stillbirth, previous low birth weight infant, and chronic hypertension were associated with an increased incidence of GDM. Women who were over the age of 35 years and with a pre-pregnancy weight of $\leq$ 49 kg or > 65 kg showed an increased risk for GDM. The researchers suggest the association between low maternal weight and GDM may be due to undernourishment or false positive GDM screen.

Naylor, Sermer, Chen, & Farine (1997) developed and validated a new selective screening approach by examining the medical records of 3131 women who had undergone screening and diagnostic testing for gestational diabetes. The women in the study were 24 years or older and at 24 weeks gestation. The researchers found that maternal age, body-mass index (BMI), and race were clinical predictors for gestational diabetes.

Others have indicated that identified risk factors are not present in all women who develop gestational diabetes. Advocates for universal screening report that testing that is based solely on the presence of risk factors may miss approximately 50 percent of women with gestational diabetes (Carr, 1998). The American College of Obstetricians and Gynecologists (ACOG) recommends universal screening for pregnant women aged 30 years or older and selective screening for those women less than 30 years of age. It was noted in one study that by utilizing the protocol recommended by ACOG, 35 percent of gestational diabetes mellitus cases would be left undiagnosed (Coustan, Nelson, Carpenter, Carr, Rotondo, & Widness, 1989). The authors suggest that lowering the criteria for screening from 30 years to 25 years is cost effective and provides a 31 percent increase in diagnostic sensitivity. Similarly, some researchers have proposed that because the majority of women who develop gestational diabetes are over the age of 24 years, screening for GDM should be limited to pregnant women who are more than 24 years of age (Carr, 1998).

Critics of a universal screening program for gestational diabetes question its utility. Some purport that a selective screening protocol is reasonable for women considered at low risk for the development of diabetes in pregnancy. Helton and associates (1997) conducted a retrospective analysis of women diagnosed with GDM, identified those with risk factors, and examined whether or not selective screening based solely on the risk factors would have resulted in an accurate diagnosis. They found that less than 1 percent of the women without any of the risk factors developed GDM during their pregnancy. The researchers also argue that central to the controversy surrounding universal screening is the lack of evidence that detection will lower perinatal mortality in this group, as the level of mortality is already low. Advocates for selective screening based on risk factors suggest to do otherwise could promote needless stress and unnecessary interventions for pregnant women (Davey, R., & Hamblin, S., 2001; Jarrett, 1997).

Barrett and Pitman (1999) suggest there is minimal benefit to universal screening for gestational diabetes due to the following reasons: 1) the test is unreliable; 2) management by diet and/or insulin does not improve the outcome for the mother or the baby, and; 3) a positive test may increase the mother's stress and

anxiety levels. Jarrett (1997) questions the cost effectiveness and ethics of universal screening when there is insufficient evidence of any benefit associated with screening for GDM. There is a paucity of methodologically sound clinical trials to support universal screening for GDM in pregnancy (Stephenson, 1993). The disputed significance of gestational diabetes mellitus on maternal and neonatal outcomes, the poor reproducibility of the screening test, and the ambiguity regarding the treatment benefits for mothers and infants are cited as concerns that warrant further research (Greene, 1997; Naylor, et. al., 1997; Okun, Verna, & Demianczuk, 1997; Walkinshaw, 2001). The disadvantages of undergoing perinatal screening and facing the possibility of being labeled at risk for gestational diabetes and being aggressively treated may far outweigh any benefits to maternal and infant outcomes.

In their 1998 position paper on gestational diabetes mellitus, members of the American Diabetes Association (ADA) reversed its previous position regarding universal screening for gestational diabetes to endorse screening based on the presence of certain risk factors. GDM screening is recommended by the ADA for pregnant women who meet one or more of the following criteria: 1) $\geq$ 25 years in age; 2) < 25 years in age and obese (>20% desired body weight; BMI > 27kg/m2); 3) family history of diabetes (in first-degree relatives); 4) member of an ethnic group with high prevalence for diabetes (Hispanic, Asian, First Nation, Afro-American, Pacific Islander). These criteria remain as recommendations in the updated ADA 2002 Clinical Practice Standards for detection of gestational diabetes.

The ADA classifies women who do not present with these factors as low risk for developing gestational diabetes and suggests that screening this population of women would not be cost effective. The Fourth International Workshop-Conference on Gestational Diabetes Mellitus held in 1997 developed a screening strategy for detection of GDM that is similar to that proposed by the ADA. In addition to the characteristics outlined by the ADA, the conference members included history of abnormal glucose metabolism and poor previous obstetrical outcomes. Schwartz, Ray, and Lubarsky (1999) examined the impact of lowering the criteria of the oral glucose tolerance test in pregnancy, based on the recommendations from the Fourth International Workshop-Conference on Gestational Diabetes held in 1998. The

researchers note that a change in diagnostic criteria would increase the number of women diagnosed with GDM as well as health care costs but only minimally affect the incidence of infant macrosomia. They suggest that the potential for false positive results could adversely affect women's stress levels.

The Canadian Task Force on Preventive Health Care (1994, 2001) concludes that the available evidence regarding prenatal testing for GDM does not support a recommendation for or against universal screening. The validity of the diagnostic test for gestational diabetes is uncertain, the magnitude of the benefit of screening on neonatal outcome is inflated, and the cost-effectiveness of screening is questionable according to the task force. Continued clinical research in the area of perinatal screening is advocated before any definitive recommendations are made either way. Pending further study, the task force supports practitioners using their clinical judgment in these cases, such as, assessment for risk factors and close monitoring of the progress of a woman's pregnancy for those with risk factors for GDM. These recommendations perpetuate the notion that pregnancy has the potential of being a risk for many women and in need of medical surveillance and interventions. Four years after the 1998 Canadian clinical practice guidelines for the management of gestational diabetes were published it is still recommended that all women between 24 and 28 weeks gestation to be screened for gestational diabetes with the exception of those judged in a low risk group.

Some pregnancies are undeniably in need of medical interventions to reduce maternal and neonatal mortality. For example, due to the high prevalence and impact of GDM and because clinical criteria alone cannot reliably identify women with GDM, screening of all pregnant women is warranted unless they are in a very low risk group (Meltzer, et al, 1998). Gestational diabetes is associated with adverse perinatal, maternal, and neonatal outcomes, including macrosomia, birth trauma, preeclampsia, shoulder dystocia, stillbirth, and increased cesarean section rates (Avery & Rossi, 1994; Naylor, et al, 1997). Women who develop GDM are reported to have a 50-60 percent chance of developing non-insulin dependent diabetes mellitus later in life (Buchanan, & Kjos, 1999; Jones, & Stone, 1998). The necessity of the contemporary treatment modalities for GDM in terms of significantly achieving

favorable maternal and neonatal outcomes is being questioned in the medical community. Research on the effectiveness of various treatments on decreasing adverse maternal and neonatal outcomes has been inconclusive.

In one study the effect of conventional and intensified management of GDM on perinatal outcomes was compared (Langer, Rodriguez, Xenakis, McFarland, Berkus, & Arredondo, 1994). The authors concluded that an intensified management approach (diet and insulin) is significantly associated with enhanced perinatal outcomes. Caution is advocated when interpreting the results as the sample was non-randomly selected and predominantly Hispanic. In contrast, it was suggested in a randomized study conducted by Garner and associates (1997) that intensive treatment of gestational diabetes may have little effect on outcomes, such as, macrosomia, birth trauma, operative delivery or neonatal metabolic problems. A systematic review regarding the management of a diabetic pregnancy revealed that there is no clear evidence of benefit on maternal and neonatal outcomes with implementing tight glycemic control (Walkinshaw, 2001). These researchers propose larger, randomized clinical trials are needed to determine the most effective treatment regime for gestational diabetes. Further, research is also advocated to address the controversy surrounding the gestational diabetes screening protocol (Helton, et al, 1997; Naylor, et al, 1997; Stephenson, 1993).

Some researchers have focused on how women react to being considered at some degree of risk simply as a consequence of being pregnant and diabetic. Previous research has been conducted to identify psychological outcomes associated with pregnancies complicated with GDM. Depression, fear and anxiety are common emotional responses elicited by women who develop gestational diabetes (Barglow, Hatcher, Wolston, Phelps, Burns, & Depp, 1981; Kelleher, 1994). In one study the association between the diagnosis and treatment of GDM, maternal depression and maternal-infant attachment was explored (Chazotte, Comerford-Freda, Elovitz, & Youchah, 1995). A group of 20 women diagnosed with and being treated for gestational diabetes was compared with two control groups, 30 women at risk for premature labor and 30 women experiencing uncomplicated pregnancies. Although no significant between-group differences in depressive symptoms or maternal-infant

attachment scores were noted, the researchers found a high overall level of depression symptoms in all three groups. The fact that all of the participants were from inner-city communities may have contributed to this finding.

To investigate psychological adjustments to pregnancy, 100 pregnant diabetic women took part in a psychiatric interview during the second trimester of their pregnancy (Barglow et al, 1981). The investigators concurred with other research findings in suggesting that diabetes is associated with maternal depression and anxiety. It was noted that 33 of the women showed evidence of clinically significant depression, another 25 reported marked anxiety and/or disruptive panic attacks, and 7 showed symptoms of psychosis. Uncomplicated pregnancies involve multi-faceted changes that can be emotionally challenging for women. The fact that these researchers failed to include a control group in their study limits their findings.

The consequence for women of being diagnosed and treated for diabetes during a pregnancy has been examined. Langer and Langer (1994) investigated the effect of intensified treatment for gestational diabetes on the emotional status of pregnant women. A secondary analysis of data from their previous studies of women with GDM (n = 206), those with pregestational diabetes (n = 100) and nondiabetic controls (n = 227) was conducted (Langer, & Langer, 1994). The researchers concluded that the diagnosis of gestational diabetes, frequent glucose testing, and insulin therapy did not have a significant negative impact on the emotional state of the pregnant women as measured by the Profile of Mood State-Bipolar Scale. They allege that the findings diminish the assertion that insulin therapy and stringent blood glucose monitoring have any adverse effects on the emotional state of the women with gestational diabetes. They further suggest that frequent glucose monitoring accompanied by continuous reassurance regarding their ability to maintain euglycemia may enhance the women's confidence in any treatment regime and their ability to cope. The results of this study are noteworthy, but have limitations. The control group consisted of women with high-risk pregnancies but the characteristics that defined them as high risk were not given. The sample consisted primarily of economically compromised inner-city residents further jeopardizing the study's generalizability.

In a similar study, the psychological impact of gestational diabetes on pregnant women's affect was explored (Spirito, Williams, Ruggiero, Bond, McGavery, & Coustan, 1989). Interviews with the women were held several weeks after they had been diagnosed with gestational diabetes. Comparable to the previous research conducted by Langer and Langer, the researchers concluded that being labeled "a gestational diabetic" did not have an adverse effect on the emotional status of the pregnant women. No significant difference was found in the psychological status of the women who received insulin therapy and those who were solely diet controlled. The researchers suggest that, over a very short time frame, pregnant women readily adapt psychologically to having gestational diabetes while pregnant.

Discretion is required when interpreting the findings of the above two studies. The women were contacted several weeks after their diagnosis of gestational diabetes was made. The required adjustments to their new lifestyles would have likely been made by that time. Most lifestyle changes and perhaps significant impact on the women's emotional state was likely to occur when they were first informed of having gestational diabetes.

Using both qualitative and quantitative methodologies in her study to examine the emotional distress associated with the diagnosis of gestational diabetes, LaPlante (1992) found that women confronting an unexpected diagnosis of diabetes during their pregnancy experienced some degree of emotional distress. The findings, in contrast to the previously reported studies, were that the women experienced grieving and the loss of a normal pregnancy in addition to problems with dietary restrictions, life style modifications, and feelings of anger and fear.

Two qualitative nursing studies were explored where women's experience of being pregnant and diabetic was described. Lawson and Rajareem (1994) conducted an ethnographic study of gestational diabetes to examine the meaning that women attach to their medical condition. The authors report that gestational diabetes had a profound effect on the women and resulted in fears, anxiety and depression. To take a purely medical view of gestational diabetes they suggest minimizes the psychological impact it has on afflicted women and their families. In a second study conducted in Sweden, Berg and Honkosalo (2000) used a hermeneutic

phenomenological approach with pregnant women who had Type I diabetes to describe the meaning of their pregnancy experience. Similar to the findings of Lawson and Rajareem, the women were reported to experience worry and constant pressure while pregnant. These findings help to begin to uncover and deepen our understanding of women's subjective experience of being pregnant and diabetic.

Research has been conducted to examine the emotional responses of diabetic women throughout their pregnancy and postpartum. In one study, anxiety, depression and hostility were measured using the Multiple Adjective Checklist (MAACL) (n= 36 pregnant diabetic women) at five time intervals ranging from 36 weeks gestation until 8 weeks postpartum (York, Brown, Armstrong-Persily, & Jacobson, 1996). Anxiety and hostility scores were higher during the antepartum period for the women with gestational diabetes than for those with pre-existing diabetes. This finding may be related to women with GDM adjusting to the diagnosis, accepting a pregnancy at risk, learning new skills, complying with a treatment regime, and making major lifestyle adjustments. The women expressed concerns for both their infant and personal well-being throughout the antepartum period. Feelings of depression were found to be highest in the immediate postpartum but diminished by the eighth week and may have been representative of postpartum blues rather than being associated with having diabetes. Unfortunately the sample size was small and included primarily Afro-American women from lower socioeconomic situations, thus hindering generalizability.

Two retrospective studies were conducted to examine women's experience of encountering a pregnancy complicated with diabetes and the long term effects on their general health and well being. In one study, women who had experienced gestational diabetes (n = 113) were sent a questionnaire several months after childbirth (Sjogren, Robeus, & Hanson, 1994). The researchers sent a questionnaire to a group of women who had previously experienced a pregnancy complicated with GDM and group of women with uncomplicated pregnancies. The women with previous GDM worried more about their general health status and expressed more physical health problems than the control group. The researchers concluded that GDM negatively influenced women's experience of health and well-being. It was

noted that many women initially felt they had a serious condition and found it difficult to accept. Significantly more women with GDM, as compared to those women with uncomplicated pregnancies, expressed memories of not feeling well, poor health, and low energy throughout their pregnancy. The women with diabetes described their childbirth experience as a negative one. These women tended to worry about their health both during their pregnancy and after childbirth.

In contrast to some of other research related to women's reactions to having gestational diabetes, Sjogren and associates (1994) concluded that the level of treatment regime might adversely influence emotional status of pregnant diabetic women. The authors found that the women who received insulin therapy for diabetes control expressed more worry throughout the childbearing period than did the women whose diabetes was managed strictly by diet.

In a retrospective study women were surveyed three to five years after they had experienced a pregnancy with gestational diabetes (Feig, Chen, & Naylor, 1998). Using the general health scale the SF-36 (general health survey) they concluded that women with the previous diagnosis of GDM felt themselves to be in poorer health than those without GDM. These women also considered their children to be in poorer health and were more worried about their own health than those women without a diagnosed pregnancy complication.

In one study explored the relationship between women's perceptions of the impact of GDM, treatment adherence, professional help seeking and maternal and neonatal outcomes were explored (Persily-Armstrong, 1996). The researcher concludes that women who perceived their diabetes as having a great impact on their lives potentially increased their risk by not adopting the recommended behavioral tasks that would affect their blood glucose levels. These same women were more likely to seek psychological, social and economic help from a health professional rather than self-care knowledge about diabetes. Persily-Armstrong concludes that women need support to resolve emotional, social and financial issues in addition to obtaining information about diabetes and self-care. The response to the diagnosis and treatment of gestational diabetes mellitus is individualistic, and based on the woman's perception of its impact to her life and her ability to cope. Primarily inner city,

unmarried, poor, Afro-American women participated limiting generalizability to other women. However the relationships found in this study between perceived impact and treatment adherence and between perceived impact and help seeking illustrate the need for health care professionals to consider behavioral and psychosocial components of risk from the individual woman's perspective.

In summary, considerable research regarding GDM has been conducted to determine effective screening and treatment modalities to reduce any adverse perinatal, maternal and neonatal outcomes. The outcomes of these studies remain controversial so further clinical research with randomized trials is needed. Investigations involving pregnant women diagnosed with GDM have shown there are adverse psychosocial outcomes. However, these studies have been limited to very specific populations and fall short of giving insight of women's personal meaning of experiencing an "at risk" pregnancy, such as gestational diabetes, and its treatment. The next chapter contains the women's stories that were shared with me about their experience with gestational diabetes.

CHAPTER FIVE

Women's stories of gestational diabetes

Stories about life events shed light on the meanings of human experiences (Parse, 2001).

Bergum (1997) suggests that, "stories are one means to recover life knowledge that has been undermined or forgotten."(p. 8). The women were invited to describe their pregnancy experience by telling their stories in their own words. For the purpose of anonymity I gave each women a fictitious name. These women's stories led to a deeper understanding of the women's day-to-day lives and a greater appreciation of their childbearing experience living with gestational diabetes.

Audrey "I was taking a risk, I need to be vigilant "

Developing gestational diabetes during her fourth pregnancy came as no surprise to Audrey. Two of her previous three pregnancies had been affected with gestational diabetes and she had large babies. She recalled that her first child had weighed over nine pounds at birth.

Audrey hoped that this particular pregnancy would be different but she fully expected to face gestational diabetes again. To Audrey and her family acquiring gestational diabetes had almost become the norm rather than an unusual event. There really wasn't much she could do about changing what appeared to her inevitable. *"This is normal for me. It's not like I went into it and was shocked when they said, 'You have diabetes.' I expected it. Dr. H. said, 'It doesn't necessarily mean that you'll have it this time.' But I knew that I would. I just figured that the odds of getting it the second time are a lot worse. So I may as well just accept the fact that I am going to have it."*

Despite being cognizant of the health risks involved for herself and her baby Audrey had made a conscious decision to have her fourth child. *"The doctor told me if I ever had another baby I would be diabetic for life. I was kind of figuring we were taking quite a risk here. Because I had agreed because Dan wanted kids. I knew"* Once the routine screening and glucose tolerance test confirmed she had gestational

diabetes again Audrey expressed *'being scared'* and *'terrified'*. She had become pregnant too soon, not giving herself the chance to lose all the weight she had gained during her last pregnancy two years previously. *"This pregnancy was not a planned one. So it took a lot of adjustment because I've had a lot more stress physically and mentally with this pregnancy. I didn't really have a lot of time to lose it* (weight) *all. So this time it means I will be a little heavier and that concerns me."*

Her thoughts centered on the adverse effect that the re-occurrence of gestational diabetes so soon after her last pregnancy might have on her future health and well-being. Audrey noticed that the amount of insulin required to control her blood glucose levels kept increasing and wondered if she might be experiencing a long-term health problem. She questioned whether she would become permanently diabetic and the effects of long-term use of insulin? To avoid the possibility of developing permanent diabetes later in life, Audrey recognized the necessity in her taking some preventive measures once her child was born. *"I think the biggest issue for me and my family is that I will be a diabetic all the time. That's probably more of an issue than during the pregnancy thing. For a lot of reasons, not because of the costs, but just because of the health complications that go with it. I just think that I've been on insulin a lot longer. This time I just feel a bit more concern about permanently becoming diabetic."* She was motivated to make any necessary changes. *"So I am really obsessive with the fact that after I have this baby I have to lose a lot of weight and really get in shape. Those things are really starting to get important to me."*

Audrey's previous pregnancies had been induced before term forcing her to deal with problems associated with premature babies, such as, feeding difficulties. She tried to breastfeed her babies but found it problematic. In talking about breastfeeding her son she stated, *"I gave it my best shot. But it's just frustrating because I know that if I could have carried him to term he would have been stronger and plus his digestive system wasn't fully developed. He had a lot of problems on the formula. And the doctor said that was just because he was early too."* Needing to be hospitalized for induction and childbirth separated Audrey from her other children at home. With her past pregnancies her babies were admitted to an intensive care

nursery for observation depriving Audrey of the normal birth experience she had always longed for. *"And I hate that. It's my fourth baby. I've never had one of them with me at birth and I find that's really hard. I just wanted to have a normal experience just for once."*

Audrey worried about having another big baby. In comparing her present pregnancy with her previous childbearing experiences she states, *"I'm scared of the baby being too big. That kind of scares me especially since my insulin and blood levels are way higher this time. So that part really scares me. Like terrifying."*

Managing her gestational diabetes was described as *"just hard"* and *" a pain"*. By her fourth pregnancy Audrey was having to self-inject insulin three times a day, an act she didn't like to perform on herself. *"The insulin and the poking, everything. It was a real hassle when you go somewhere."* Her daily activities had to be rescheduled to accommodate her prescribed diabetic regime. The constant blood glucose monitoring became a task that was never easy. *"You're supposed to take your blood sugars 4 times a day. Well, there are times when my schedule didn't fit. Especially because I worked shift work. And it's really hard to fill their little book and write out everything."* She reported that the supplies needed to manage her diabetes posed an additional cost to the family, as they had insufficient medical coverage.

Audrey's past experience with and her knowledge of gestational diabetes affected her thoughts about having developed it again. Although she was scared, Audrey expressed having a familiarity with its management and a lessened stigma attached to having gestational diabetes once again. In considering her current pregnancy Audrey considered diabetes management as *"not like a big deal"* as compared to how she felt with her previous pregnancy experiences. She continued to socialize with friends and self-administer insulin in public places. She wasn't concerned with what others thought about her having diabetes. When out in public setting Audrey tried to ignore the curious, those wondering if she was an addict. *"I even just take my pen with me if I go out somewhere and eat. I just pull my pen out and like right through my pant-leg. I got some funny looks sometimes ...but then you*

almost feel like, 'Oh yeah! You're shooting yourself up in public! (laughs). I don't see it as something to be ashamed of."

As her pregnancy progressed and Audrey became attuned with her bodily responses she was less structured permitting some flexibility in following her diabetic regime. *"There were times when I didn't check it 4 times a day. I wasn't really concerned because I knew that the insulin I was on was controlling it well and I knew I was watching what I ate and I knew that it was working."* She selectively used the information health professionals provided her and incorporated only what she considered useful in managing her diabetes. *"I found that you just kind of have to take what they say and sweep some of it under the carpet and do what works best because it's very expensive."* She amended her regime as needed to accommodate her specific individual needs.

However exercising diabetic self-care throughout the pregnancy was restrictive leading Audrey to a sense of resignation. The fact that her diabetes had to be acknowledged and dealt with was outside of her control and influence. *"In a way I felt my life was like controlled. You're supposed to watch your diet at all times now, particularly when you are pregnant. With gestational diabetes you don't really have a choice. It's not a matter of you having to make a healthy choice, it's a matter of that's the way it is. There is no way around it."* Through her experience with diabetes Audrey became aware of what she could or couldn't eat when she attended social gatherings with family or friends. A piece of cake became more than mere empty calories but something that will affect blood sugars and may be harmful to her baby. *"Like we go to a birthday party somewhere; everybody else is eating cake and ice cream. It's not a matter of thinking about it because of your weight. It's a matter of thinking about it because you know your blood sugars are gonna go sky high and that it's dangerous for the baby so you don't eat it. It's more like the choice is made for you. I suppose you could still go ahead and do it but it wouldn't be a very wise decision."*

For Audrey, her responsibility and moral obligation to keep her unborn baby safe throughout the pregnancy was paramount. *"It's not just yourself. If you're just diabetic yourself, to think about what the risk is to yourself, the signs, the symptoms,*

and whatever. I might be feeling fine and it is affecting the baby. That's the part that you worry about and you emphasize to people. Like it's not just yourself you're thinking about. You have one that is totally dependent upon you to keep it safe." For the sake of her baby' wellbeing, Audrey felt compelled to effectively manage her diabetes by trying to control her blood glucose levels. She tried to stay the course and relied on the health care team to help ensure a good outcome for her baby. *"It's really risky for the baby. I would tell anybody to do what they tell you to do and keep your blood sugar's as stable as possible for the sake of the baby. Because I have seen a diabetic baby when they are first born. It's just really scary when a baby's sick."*

Throughout her pregnancy Audrey remained vigilant and advocated for her unborn child. She drew upon her experiential knowledge from her past pregnancies to act in what she perceived was in the best interest for her self and her unborn child. To obtain prenatal care with her third pregnancy Audrey stated, *"I think if you have health problems you're more concerned with something that's different. I kept telling him my blood sugars were running a bit high and he did the screening test and it came back kind of border line and he said, 'Oh, you're border line and I'm not really going to worry about it.' So I was the one who really pushed the issue. He just said he wasn't concerned if I was to do it at a later date. I was already quite pregnant with her and I kept checking myself. So I just kept pushing the issue with him and I said, 'Well, what do you normally do?' because I might have known from my experience 10 years before that. So he said he normally sends his clients to see Dr. R at the diabetic clinic. I said, 'Well can you at least let me go talk to him and see what he thinks?' And on the day I went to see him they put me on insulin. I was concerned about the baby. She was 4 weeks early. She was just under 7 pounds so the insulin did help because S. was earlier than that and she was 8 pounds 6 ounces."*

During her labor and delivery experience Audrey faced conflict in her interactions with some health professionals concerning her diabetes management. She found herself a recipient of patriarchal treatment. *"I think they need to give the moms' more credit. That we know what we are doing."* In describing the hospital nurses she stated, *"They would come in every so many hours and say, 'Ok take your insulin 'cause your food is gonna be coming up right away.' And they'd stand there. I*

mean you've been doing it for how many months and they stand over you and want to watch you take your insulin. Well, I would rather see what I'm gonna eat first and then take my insulin. It's not like you are a new diabetic and you don't know a thing about it. I've been taking insulin for a couple of months. I knew that if I wasn't going to eat I didn't want to take the insulin. Plus my blood sugars weren't that high. And then I would force myself to eat because I took the insulin. I could have quite easily just done without." She felt that she lacked recognition from others for the knowledge that she had.

The physician had instructed Audrey that once she was in labor to take insulin only if she eats something. She shared this information with the nurses when she arrived at the hospital but was met with confrontation. *"Dr. R gave me a piece of paper to take in and he said, 'Just give this. These are my orders.' I gave them the paper and they're still, 'Oh what's Dr. R's policy with gestational diabetes. It's like they don't take your word for it. They have to look everything up. They were debating back and forth between them because they weren't sure which was Dr. R's policy and which was the other doctors. And I was sitting there listening, 'Why don't you just look at the paper. I can understand it. So what difference does it make? Why do you have to pull policy and procedures just to find out what he's already given to me to give to you."*

Audrey felt that the significance of gestational diabetes on her health was not fully recognized by her spouse. *"I don't think he really knows what normal is. I get really frustrated with him sometimes. I don't think men really understand what a woman goes through. He says he does but he doesn't. ' I don't think that he understands that fact that this actually could cause me to eventually be on insulin for the rest of my life. It increases my risk. A lot of times he will talk about his risks and he'll talk about things that he has or he'll go, 'Oh yeah, my dad's diabetic so I could be a diabetic some day'. And that seems to stand out to him. He doesn't like the fact that being pregnant is jeopardizing my health but like if I said I'll have ten kids, he'd say, 'Let's go for it! It doesn't occur to him that my being pregnant increases my risks. So then I tell him off."*

Audrey sensed that her family and friends were ignorant of the problems she faced with her babies being born prematurely. They seemed to question her mothering ability. In describing her son's bout with diaper rash she explained, *"When you have gestational diabetes your babies are a bit early. And then with him it was like even if people felt like, 'Why is it so raw? Why is his bottom so sore? It was almost like am I keeping him clean? Or am I doing the right thing? When I would say, 'Well his digestive system isn't fully 100% developed.' They say, 'Well, he's a nice healthy size. He shouldn't be having any problems.'"* She tried to dismiss their comments. *"And I just think 'Whatever!' They just don't understand it."*

Audrey's pregnancy ended by a scheduled induction at 37 weeks and she vaginally delivered a healthy baby boy weighing 7 lb 7 oz. She described her labor as long and the worse she had ever experienced. *"It was like one incredibly long, long, long day. It didn't let up. I was just gonna die."*

This time her baby was not admitted to the intensive care nursery and Audrey was able to be with her son. Gestational diabetes and her son's development of jaundice led to him suffering frequent heel pricks to monitor his blood glucose and bilirubin levels. Audrey was furious when she first saw her son's foot once she got home from the hospital. She questioned the staff's competency in looking after her son. *"I'll tell you that I really resent about gestational diabetes is that when the baby is born they poke him in the heel and they are not very good at it. I was mad when she pulled that Band-aid off and I saw that cut. He had that long cut on his heel. ...all the way up the side of his heel was cut and it was deep and the heel was just black. That part of it really upset me that they had to check his blood sugar that frequently. Every three hours. I know they had to do it but I think I could have done it myself and done a better job."*

At home Audrey continued to test her blood sugars and at 6 weeks postpartum went for a 3-hour glucose tolerance test. She reported that the diabetes was gone and her blood sugar levels were back to within a normal range. As I sat with Audrey in her living room she stated this would be her last pregnancy. She stated, *" It just wasn't a good pregnancy. The last month was horrible. I'd never do it again. They couldn't pay me to have another."*

Barbara "What's going to happen?"

Barbara began her story by recalling the fear and shock she felt when she first encountered gestational diabetes during her second pregnancy almost three years earlier. She was 28 weeks pregnant when the results of a routine blood-screening test caused an abrupt change to her second pregnancy experience. Pregnant with her third child, Barbara was now facing gestational diabetes for the second time, something she had hoped would not have transpired. Barbara's first pregnancy had ended in a miscarriage early in the first trimester.

Managing her diabetes instantly created a challenge that Barbara needed to acknowledge and somehow overcome. The required lifestyle changes and restrictions affected both her personal and social activities. Her daily activities became regimented, restricted and evolved around scheduled-clocked time. *"It was just the diet, the lifestyle, the making sure that you were on such a schedule. You got up. You had to eat. You had to do this. You had to do that. You had to make sure you took your insulin and you had to make sure that you were prepared to take the insulin at the proper time and that your food came if you were in a restaurant or if you were at a party or something like that. That you stayed away from all the snacks. We go places now and people say, 'Oh do you want some of this?' 'No thanks, that's OK. I have to wait my two hours to do my blood test and I don't eat anything between that time. So everyone's sitting around eating chips and dip and you are going, 'I still have an hour left. And it can be a little trying as food is the center of it."*

With her previous pregnancy Barbara felt that she had little time to adjust to the required changes as the diagnosis came late in her pregnancy and she would soon have her baby. Once she was told about being diabetic things in her everyday life immediately started to change. She recalls being told, *" 'You've got diabetes. This is what you have to do.' And then you have the baby and you really don't have a lot of time to absorb. Like the first time we were kind of thrown into it. We didn't have a lot of time. I went at 28 weeks for the test and by 30 weeks I think I was on insulin."* She felt overwhelmed, faced many uncertainties and worried about what lay ahead for herself and her child. *"You worry about what is going to happen, how you have to deal with this and everything else. Is the baby gonna be OK? Is there gonna be any*

long-term effects? What happens if it doesn't go away? I was really scared about shorter life span, heart problems. Everything goes through your mind. Am I going to be around to watch this kid get married?" Developing gestational diabetes led Barbara to question her culpability surrounding what happens to her baby. *"Is she going end up with diabetes because I had it?"*

During her first encounter with gestational diabetes Barbara kept her questions and feelings to herself. Who could she talk to about what was happening to her? Who would understand how she felt? Initially diabetes was totally overwhelming and she felt uneasy and unsure about what it meant to her. *"The first time around I was just so scared and so concerned and so worried I didn't feel comfortable asking. I was uncomfortable with the situation myself. And the first time around the pamphlets and everything they gave you, you read and stuff but it didn't help you very much in the sense of the way you felt."* Diabetes had a negative connotation for Barbara causing her to wonder how others would perceive her once they knew. *"I didn't have anyone to talk to about it. I know I went to the doctors. I went to the dietician and the nurses and everything but how do you talk to them and say, 'Gee, I'm really embarrassed because of this diabetes and it's caused by this and this and this and you know how are people going to look at me and, 'Oh, You have diabetes!' "*

Although Barbara told her husband and immediate family members about having diabetes she was embarrassed about her circumstances and hesitant to tell friends and acquaintances. She was uncertain about what people's reaction to her would be once her diabetes and need for insulin was revealed. In an effort to keep her diabetes concealed Barbara hid any evidence from others. *"At first I was embarrassed so I didn't tell anyone. My husband knew. My family found out. I told them but we didn't tell a lot of friends or stuff like that until I was comfortable doing it. Until I was comfortable taking the insulin. Until I was comfortable with what was going on. It's one of those things that you don't go out bragging about immediately! So it was hard at first. I would always go into another room and do things and do the insulin. For probably the first 3 or 4 weeks. I mean I had my little food sheet and I had it on the side of the fridge so no one could see it. Everything was always put away."* It took until near the end of her first pregnancy for Barbara to feel competent enough in

diabetes self-care to tell others. She described how she needed to feel comfortable with the fact that she had diabetes and that she could deal with it.

As a precautionary measure Barbara underwent a glucose tolerance test early in the first trimester of her second pregnancy. To her dismay she found that her blood glucose level was already elevated. Barbara felt prepared for the prospect of living with GDM once again, just not so soon in her pregnancy. The knowledge and skills she had acquired during her first pregnancy experience facilitated an easier adaptation to diabetes a second time. Barbara knew what to expect and consequently she felt adept at quickly taking control of her situation. In contrast to her first pregnancy experience, Barbara was more relaxed and less self-conscious about being diabetic. For Barbara feeling at ease with having and effectively managing her diabetes meant being *"comfortable with what is going on."* In describing her second pregnancy Barbara stated, *"Maybe I'm in such a groove now. I think I learned more the second time around. The second time around I had asked a lot more questions about this and that. I've been through it and I know more now. I'm not so embarrassed to ask questions."*

With her second pregnancy Barbara was less concerned about the reactions of others when testing her blood glucose or self-injecting insulin in public. Her acquired experiential knowledge led to a heightened level of self-confidence in her ability to effectively manage her diabetes in public. *"At first you didn't want to go anywhere because you didn't want to have to deal with this but when you got to be comfortable with it. It's a lot easier to deal with other things. Going out with people, going out with friends and stuff like that. And the first time I ever did it* (inject insulin) *in public somebody watched me and it was a mother and a little girl and it was no big deal. You just do it so people then can't really see and so it's no big deal for me now to do it in front of people. I will ask people if we are out, 'Are you squeamish about needles?' 'No!' So then I will do it because I actually found that more people wanted to see what you are doing than not see."*

Diabetes took on a different perspective for Barbara as she became more relaxed with its management. The negative stigma she had initially attached to diabetes and to herself as a person with gestational diabetes diminished. She

concluded that having diabetes doesn't change who she was as a person. Barbara explained her view of diabetes needed to be put in different light. Diabetes can be serious if not well controlled but Barbara realized that it really didn't matter what people thought. *"It's a big deal but it isn't a big deal. It's a big deal but it's not a big deal to be embarrassed and to not do it because you are scared that people are gonna talk. It's just a part of life. It is a big deal in the sense that it is a problem. If you don't get treated for it you are in trouble. But the big deal I am trying to stress is taking the insulin. You shouldn't have to make a big deal about it. You shouldn't have to hide from it. You shouldn't have to be embarrassed about it. You shouldn't have to be secretive about it. There's nothing wrong with letting people know about it. It doesn't change who you are any way."*

When friends confronted during her third pregnancy Barbara was forthright in saying that yes she had developed diabetes again. *"Right away when I got pregnant they all, 'Are you going to have to get that diabetes thing?' 'Oh well. I'm already doing it.' It's not a big deal. Now I leave my blood, my insulin on the counter where I can remember it. Where I can do it. If people ask, hey, it's no big deal! I may do it in restaurants now. I used to run to the bathroom all the time before. I'm more comfortable with it. I am not as worried about what everybody thinks of it anymore. We found out people are a lot more understanding than you give them credit for."*

Barbara dealt with the challenges that gestational diabetes presented to her. She acknowledged the reality of its presence and tried to make the best of her situation. She couldn't make the diabetes go away. In trying to look at things from a positive standpoint Barbara stated, *"I guess the worse part about having it is getting worked up about it. You have it,...deal with it and try not to be embarrassed about it. Try not to worry so much about it that you can't enjoy your pregnancy. You try and enjoy your pregnancy even though life isn't perfect. Some things you just can't control. You've got to live with it, deal with it. Enjoy your pregnancy. Like the last month when I was pregnant with her I was much more comfortable with it and I enjoyed her last month of my pregnancy. As opposed to when I just found out I had diabetes and I was going through all the scare and the worry."*

As she became more comfortable in managing her diabetes Barbara found that she was less rigid with her scheduling and diet plan. In contrast to her first experience with gestational diabetes she remained flexible in scheduling her activities and controlling her diet, normalizing her pregnancy experience. *"Like the first time they gave you a diet. What's on the list is what I ate. If it wasn't on the list I didn't eat it. The second time around it had been so long. Basically all my pregnancy I was saying, 'Can I eat this? Can I eat that? Well yeah, you can eat this. Just read the label. I learned a lot more on how to read labels. How to enjoy the little extras without feeling like you're losing out on something. And the first time it was, 'Two hours to do the blood. I've got to make sure I eat!' I was very structured and I was very, very picky. I've learned over the past nine months, 'Yeah I can eat anything!' Just how much I want it. Just control how much you eat, then that way you don't feel like you're losing out on something and you don't feel like you're missing out on something. I don't need to eat cake everyday but there's a special occasion so I'll have a little piece."*

Worries about her children's health remained constantly on Barbara's mind. She pondered what influence gestational diabetes might have on the future health of her children. *"I still wonder if the baby's going to be OK. I keep hoping that it will be OK because the sugars have been controlled at an earlier stage. Maybe it has a better chance of being healthier down the road. It may not have the same problems that maybe she might have, because it wasn't caught at a later date."* She questioned about adverse effects that gestational diabetes might have on her toddler's health. In speaking about her second pregnancy she stated, *"It was caught at a later date and so maybe she may have some problems with her sugars down the road. I am more concerned about that one as opposed to this one because it was caught so early."*

Like many of the women I spoke to, the continual scrutiny and questioning by others of Barbara's actions throughout her pregnancy was annoying. She encountered oppressive relationships with others, which threatened her self-determination. Whenever she left a room she was expected to provide an account of where she was going, why she was leaving and what she was doing. The sudden expression of concern shown by others for her welfare was something that Barbara was not used to.

"I felt a little uncomfortable because I'm not used to people worrying about me. I mean, everywhere I went. Everywhere we went I always carried my own pop. So whenever somebody said, 'Would you like something to drink?' I'd say, 'Do you have anything diet?' 'Oh no! Well you know what? I've brought some of my own. I just took care of myself.' So it's kind of weird when someone is worrying about what you can and can't eat.

Barbara described her husband's reaction to the diabetes as mixed that is, caring but not that helpful. *"He's pretty good, for the most part. You know it's, 'Honey I have to eat now.' He'll help me find a snack. Although it's more of an inconvenience kind of thing."* He had difficulties adjusting to her changes in diet and meal scheduling and expressed embarrassment when she administered her insulin in public places.

Being closely monitored and observed throughout her pregnancy by health professionals was a significant source of relief and indicative that she was being well cared for. *"It was controlled and it's been monitored. It's really been taken care of. So I am not as concerned because I think it probably has a better chance of being a normal pregnancy. It makes me comfortable to know that they are making sure that things are gonna be OK."* Barbara's story reflected the continual need to be watchful not only while pregnant but also after the birth of her baby. *"I think it's going to be something that I have to keep an eye on and get enough exercise."*

Barbara delivered her second baby at 39 weeks by a repeat cesarean section. After delivery she continued to monitor her blood sugar and noted that her levels were back within a normal range. Encountering diabetes had a positive outcome for her. Barbara felt she had gained the knowledge and skills to control how her future unfolded in terms of what life style choices she makes. The life style changes became internalized and considered part of her normal routine. *"I've changed a lot of habits. You do it for 9 months. That's close to a year and after awhile it becomes a habit. Which is good. I think it probably wouldn't have happened. I know the eating properly wouldn't have happened. I wouldn't have made the food diet changes. It's so much part of your lifestyle."* The knowledge that Barbara gained through having had this experience heightened her perception of self and her ability to make changes for

herself and her children. *"I've really learned over the last 9 months, 'Yeah I can eat anything!'*

Uncertainty of long-term health outcomes lingered into the postpartum period. Her diabetes may be gone as indicated by her normal blood sugar levels but Barbara questioned her chances of it returning in a subsequent pregnancy or later in life Type II diabetes as being inevitable. *"Without being pregnant. Like I'll have Type II later on. I guess you could say I'm concerned whether it happens 6 months down the road or two years down the road or ten years down the road. You know that's a concern that will always be there. Will it come back? So it concerns myself and it concerns both my kids. That having passed on my genes to my kids and having them having problems down the road with it. I'm still concerned about that. That they will get juvenile diabetes."* Barbara expressed her motivation to make any necessary lifestyle changes to avoid the above scenario. The continual wondering about the future health status of her self and her two children was always present under the surface of Barbara's thoughts.

Cathi "Reclaim my body"

Stating that, *"diabetes runs in my family"* Cathi wasn't surprised to learn that she had acquired gestational diabetes. The possibility was always there she thought, as her mother had experienced gestational diabetes and now had Type II diabetes. It was getting pregnant that Cathi didn't expect as she had already experienced two miscarriages. She welcomed this pregnancy and told me she looked forward to becoming a mother.

Late in her second trimester Cathi noticed that she was becoming increasingly tired. Initially she attributed her constant fatigue to working fulltime and having a heavy work schedule. Cathi was familiar with diabetes and knew she had already experienced some of the signs and symptoms. Facing her symptoms she thought, *"Ok, I'm either hypoglycemic or I'm diabetic. It's one or the other. For me it was the process of elimination."* After discussing her concerns with her mother Cathi begin checking her blood sugar levels. She soon discovered that whenever she was tired her blood sugars were high and she proceeded to bring her results to the attention of her doctor. A glucose tolerance test was performed confirming what Cathi already

suspected; she had gestational diabetes. Cathi confessed that her past eating habits were never particularly healthy and likely a factor in her developing diabetes. She reasoned, *"Well that figures, I loved my chocolate. Once I week I was going for my peanut buster parfaits. I figured as much."* Having the diabetes confirmed meant she could begin to deal with it.

Similar to most of the women, adapting to her diabetic regime presented many challenges for Cathi. Her diabetic management entailed forcing limitations on her diet and daily activities, following a strict schedule, being under constant surveillance, and justifying her actions to others. As she started to manage her diabetes Cathi described her situation as, *"It's horrible! Everything is so strict. You can't do this. You can't do that. It's a pain in the ass. You've got to poke your finger, draw the blood out, put the blood on the sample and wait for it. I was doing it 4 times a day. If you are working full time just four times a day is excessive. It's too much. And it's expensive for the strips and lances. My eating habits are so much more different. I'm eating about six times day. I have never eaten that much in my entire life. Everything is small portions. I'm not used to portions. I get up,...I have my breakfast.* She developed high blood pressure in the latter part of pregnancy necessitating additional treatment. *"I am on strict bedrest right now so I'll go back to bed and lay there and read for awhile. I'll get up for my snack. Then I go back to bed and have nap. Then I get up for lunch."*

Throughout her pregnancy experience, Cathi struggled to cope with her yearnings for chocolates and attempts to practice restraint. As she spoke about her cravings she said, *"It was awful! 'Cause I really, really wanted it and I knew I couldn't have it. I had to stay away from it. I had to say, 'No!' And I really didn't like that."* Cathi survived by using some sugar and at times hiding chocolates from the watchful eyes of her husband. She compared her actions to that of an addict and at times was condescending stating, *"I've been such a good girl for a week now. I need my sugar fix. I feel like junky. I'm just waiting for my next sugar fix."*

In speaking about her common-law husband Cathi stated, *"My boyfriend is too strict. He monitors everything! Right down to the little tiny ounce of chocolate I am gonna have. He says, 'You know you aren't allowed to have that.'* Cathi needed to

justify to him what she could or couldn't do and to maintain some control she confronted his reactions to her behaviors. *"I had to take out my diabetic chart that they provide you and prove to him that I'm allowed to have a half a cup of ice cream. He's almost fanatical about it. If I reach for the salt shaker he's like, 'What are you doing?' I feel like he's my parole officer almost."*

In discussing her interactions with others, Cathi described a dichotomous nature to her being controlled and scrutinized. Her autonomy and self-determination was diminished as others watched and questioned her behaviors. She was expected to take on a subservient role in her relationships with others. However, Cathi's husband's controlling behavior towards her was indicative that *"he cared."* Cathi had four ultrasounds performed throughout the pregnancy to determine her baby's growth. The size of her baby was a concern as she had read about women with diabetes having large babies *"I am wondering how big it is. If it's ok. If it's going to be healthy."* The constant surveillance through technical means during her pregnancy helped to reveal the health status of her baby and was reassuring. Although frustrating, Cathi considered being under constant observation by others was evidence that *"they are taking care of me."*

As I sat at her kitchen table during our first visit Cathi offered me a cup of coffee. I declined her offer but invited her to make one for herself. I remember watching her pour some coffee to which she added sugar and sweetened whitener. My initial thoughts were how horrid that would taste. Then I wondered. Was she testing me to see my reaction? Was I to judge her too? Did my indifference at what she drank mean that I didn't care? She poured and drank her coffee as we continued our conversation.

Cathi attended a diabetic clinic to obtain both medical care and information about managing her diabetes. She continued to face difficulties adhering to her recommended regime and her attempts to inform her doctor were in vain. Cathi found herself in a highly paternalistic relationship with her doctor where her expressed needs were not heard. Her inability to follow his prescribed regime was perceived as being noncompliance. *"He wasn't listening to me. He gave me some medical laboratory tests so I could take three tests in one week, at the lab, to get my*

blood sugar done. They would test my sugar level there and I would test it 5 minutes later. And then we would match it to see if his machine was working correctly. And I was trying to explain to him but between appointments, working full time and seeing him once a week, and going to Lamaze classes I didn't have time to run to the lab 3 times in one week. I'd managed to get it done once, like one time in one week and he was so mad at me. Just the way he was, 'Oh, you're not doing this' or ' you're not doing that right.' " She is judged as being defiant. *"' I told you to go and do this but you didn't do it. Shame on you!' I felt like I was being chastised like a little girl."*

Cathi was assertive in confronting her doctor to explain her needs. *"I am thinking, ' OK, are we doing everything by the book or am I gonna follow what my body is telling me.' It felt like it was either his way or no way. Because he was the expert and he went to school. He reminds me of somebody who will who comes into the hotel industry who's never worked in the industry before they went to school and took everything about it. So they are gonna come in and they are gonna tell you that it's gonna work this way and that way. And you're looking at them and going, 'realistically that doesn't work that way in the real world. I know you want me to do this and you want me to do that but realistically it doesn't fit in my schedule. I can try but I can't."* Her unsuccessful attempts in being heard led Cathi to stop visiting this particular doctor and to rely on her mother and obstetrician in managing the diabetes for the remainder of her pregnancy. *"I just couldn't deal with him anymore. I stopped going to him. He was driving me crazy making me feel like I was doing everything wrong."*

Cathi turned to her mother for support and advice about controlling her blood sugar levels. Dissonance within Cathi's interactions with her doctor emanated from the discrepancy between the advice of her mother and that of her doctor about diabetes control. *"He said that my sugars were really out of whack there for awhile. And he had me testing it an hour after I ate and Mom tests hers 2 hours after she ate. So an hour after I ate my sugar levels were still really high. He told me if they didn't come down then he would put me on insulin. So I was talking to my Mom about it and my mom said, ' Why don't you test it an hour after you eat and then again 2 hours after you eat to see if there's a difference.' And I found a difference. Within 2 hours*

my sugar levels were back to normal." When Cathi told her doctor about her mother's advice she was informed that her mother was a nonprofessional and not a valid source for information on diabetes management. *"He started giving me flack about it and I was thinking, 'My mom's been dealing with this for a long time now. And I am sure genetically I am like my mom. If my Mom says, 'Try this' or 'try that', like she knows."*

Cathi was challenged in her attempt to gain respect from health professionals. To achieve and maintain some control regarding how her diabetic management would unfold and accommodate her needs was critical for Cathi's ability to cope. For example, she spoke with the dietician about making modifications to her diet to better fit with her schedule. In discussing her diet she stated, *"There was no way I was going to try and work full time and follow this diet according to their time. I put my foot down. They modified it and changed it. They pushed my times back to accommodate me. Because I told them, 'I'm not getting up 4 hours later to eat again. I'll sleep in and I'll skip it and I'll just start my meals later.'"*

In the final weeks of her pregnancy Cathi developed pre-eclampsia necessitating being placed on strict bedrest. Her pregnancy ended by cesarean section and she spent the first few days postpartum in intensive care for close monitoring. Her baby was born healthy weighing 7 pounds 2 ounces. Her blood sugars came within the normal range in early postpartum period and Cathi states, *"I was happy, happy. No more monitoring. Like I said 4 times a day is unrealistic."* She went home at five days postpartum and continued with the dietary changes she had made while pregnant. *"I watch what I eat. I'm more careful about it now. I'm just more careful. Because my mother's diabetic. And she was diabetic when she was pregnant. She's diabetic now and it took 20 years for her to become diabetic. I just want to get on with my life. Get my body back. Reclaim it. Reclaim my body."* Once she got home Cathi enjoyed the time with her new son but was left with other lingering thoughts. She pondered upon what the future will hold for her baby's health. *"I wonder if he's gonna get it when he's older."*

Diane "It's so much more"

During her second pregnancy Diane underwent a blood glucose-screening test as part of her routine prenatal care. She remarked that her first childbearing experience wasn't taken as seriously and couldn't recall ever being tested for diabetes. Her blood sugar levels came back high prompting her physician to send Diane for a blood glucose tolerance test. Diane was shocked at her results and immediately sought a rational explanation. To be diabetic was a difficult concept for Diane to believe about her self. She considered herself as being healthy so how could she be diabetic? If having diabetes is true why doesn't she feel sick? *"No, I can't be because I am healthy. I've never really had a sugar problem. Deep down I didn't think I had a problem. I don't drink pop. I didn't feel any different. I didn't really believe him in a sense. At the same time I was upset because I was watching what I ate. I'd been stressed though and I didn't realize that stress plays a role in it."*

Although the results of her blood glucose tolerance test fell within a normal range Diane was asked to return to the diabetic clinic for diet counseling. Diane complied but feelings of discouragement arose in light of her normal blood sugar results. *"Having to go when they said that my level was normal, that was discouraging. I didn't think there was any need for me to go to the diabetic center but my doctor wanted me to be aware of what to do in case it should happen again. It gets a little discouraging because you are constantly,...constantly going. You're always going to the doctor. Like I never go to the doctor. Now that I am pregnant of course you go to the doctor. But I said, 'My god! How many doctors? How many things do I have to go for? So it does get a little discouraging. But I thought 'Ok'. I had no problem with doing it. I'm going to do it. I'm not going to argue with him. But it was just something else that I had to miss time from work. But it was important. We had to be sure. I had to know how to eat properly. I'd have to change my eating habits and do my blood test daily."* She agreed to follow what was suggested to her for the sake of her baby's well being.

Her words also spoke of the challenges and fears associated with her diabetes management. *"Just scared because even though you're in your third trimester you still have to take your blood sugar and you still have to test your urine and stuff. You*

have to eat properly. It's like this would be an everyday thing and when they check you at the hospital seeing how you are progressing if you are. It's just that much more (having diabetes). *Why can't you just have a baby? Why does there have to be so many things?"* Her pregnancy was transformed into being a complex process. When Diane first became aware of her high blood sugar levels she tried to take control of the situation and remain hopeful that everything would work out. She decided to be proactive and put things in perspective in terms of how she could manage her pregnancy. *"I did worry about it a lot there during that week but at the same time I had to calm myself down because it was like, 'It's not the end of the world!' So I had to just, take charge. If I did have problems with it then do something about it. It's not something that you can brush off. I was worried. I was stressed. I was concerned and what not but it was always, you've got to keep faith. You know it's going to get better and you have to make it work."* She started to research as much information as she could about pregnancy and diabetes.

When she attended the diabetic clinic for follow-up care Diane discovered how serious gestational diabetes can be for her self and her baby. Although she knew about her potential of having a large baby she was unaware of possible developmental problems. In addition to her concern about having a large baby she now had other worries. *"I know it can be serious. I was aware that the baby grows quite quickly when your sugar level is high because the baby is receiving all the sugar. But I didn't know about internally. All the organs are developing. At the time I thought my sugar level was doing OK so I was getting a little worried. I was thinking having a big baby. If the baby's going to be big that's gonna be difficult. So size is a concern and then to find out about the organs."*

Although her blood sugar levels didn't increase for the remainder of her pregnancy experiencing diabetes changed Diane's perception of pregnancy. Her diabetic diet was in contradiction to her original thoughts about eating habits while pregnant. *"It is interesting finding out what you have to do in order to have a healthy baby. You quit doing things for nine months just so you're healthy and the baby's healthy and then to have your sugar level. It's almost like, 'Oh my god! This is the time when you are supposed to eat.' When you are supposed to indulge in cakes and*

cookies and all of that." Attending the diabetic clinic facilitated Diane to make necessary dietary and lifestyle changes. *" If anything it showed me how to eat better, to eat healthier. It was very educational about juices. What's all in juices. It says unsweetened but there is actually a lot of sugar in juice and I thought, ' Well, Ok, no juice for me any more.' Stick to more natural."*

Diane stressed the heightened importance of her being cautious in managing her diabetes for the sake of her unborn baby. She was willing to sacrifice her needs being met to do the right thing for her baby. *"That's the most important thing you're thinking about is your baby's health. You just want to take as good care of yourself as you can. If I keep watching what I eat. Like more things to have to take care of for myself and the baby. It's not enough that you are trying to be careful at work. You're trying to be careful that nothing happens. Like being careful in a sense where I just don't want to damage myself or my baby. I don't want to lose the baby."* To be screened for gestational diabetes was an act of selflessness for Diane. *"I mean like you can't be selfish and not want to know. You have to know for the baby. And you want to stay healthy too because if you don't take care of it then you're gonna get overweight and the baby's gonna be bigger. And you want to make the birth as easy as you can for yourself."*

Diane's husband and other family members showed concern around her diet throughout her pregnancy and when she was breastfeeding. The focus of her husband concern was to ensure Diane 's actions were in the best interest to the baby. *"My husband, he was concerned. He wanted to make sure that I was always eating. Basically getting the right kinds of foods. If I go skipping a meal because we are running around or something he'll get upset because it's important in producing the milk for her. So he wants me to breastfeed as long as I can and while I am he wants me to eat right."*

Diane remained on a controlled diet regime throughout her pregnancy and successfully kept her blood sugars within a normal range. Her labor started spontaneously at home and she gave birth vaginally to a healthy term baby weighing 7 pounds 5 ounces. A positive outcome of her pregnancy experience stated Diane was finding that the required dietary changes she had made throughout her pregnancy

were now habitual. She was motivated to continue her dietary changes to avoid health problems in the future. *"I still want to eat properly, it's a concern, right."*

Ellen "Doing the best that I can"

When Ellen saw her doctor early in the first trimester of her third pregnancy she was informed that being 38 years old and having had high blood pressure placed her in an 'at risk' category. To discover, through a blood glucose tolerance test that she had also developed gestational diabetes was *"scary"*. Ellen considered diabetes a serious condition and something that she couldn't ignore. Although her blood sugar levels in her previous pregnancies had always been borderline she recalled, *" In my previous pregnancies I didn't quite have to go to this point, go to the clinic and have all this treatment."* Ellen was embarking on a new experience and had little knowledge of what to expect for both herself and her baby. This pregnancy was *"not as easy"* as her previous ones and Ellen felt *"kind of disappointed."* She questioned what was going to happen next.

Six weeks after being diagnosed Ellen had her first appointment at a diabetic clinic for follow-up diabetic care. Prior to her first clinic visit she searched for any information about diabetes in pregnancy and how she could begin to manage it. *"There was nothing much I could do except do as much research as I could on my own. So in the meantime I just had to watch what I ate and be careful to not eat too much sugar and too much fat."*

Dealing with her gestational diabetes soon became a source of stress as her sense of autonomy diminished. She described herself as someone who was usually in control of factors influencing her life and daily activities. To live with diabetes presented a situation in which her ability to stay in control was continually challenged. Her body reacted and responded to forces independent of her conscious self. She talked about the struggle trying to keep her blood sugars within the recommended range by following her regulated diet and exercise regime. Ellen's efforts proved to be futile and ineffective. Her body she explained became like a separate entity, divorced from her influential thoughts and actions. It was out of her control and eventually she required insulin. *"I'm used to being in control of everything. It was being totally out of my control. There didn't seem to be anything that I could do that would help. My*

own body, it's not doing what it is supposed to do. No matter what I ate, no matter what exercise I did; it just didn't help my blood sugars. They just did whatever they wanted. And then when I finally got to see the dietician and got a diet laid out for me and all of that for one week it didn't do much with my blood sugar so they put me on insulin. And the diet didn't do much so the only thing that was gonna do anything was starting insulin."

Ellen continued to attend the diabetic clinic throughout her pregnancy and religiously followed her diabetic regime. She concluded that alternative actions weren't available to her and resigned to the fact that she needed to accept her diabetes and simply adapt. Having gestational diabetes was genuine and something that she couldn't deny or eliminate. However, trying to deal with her diabetic management regime was arduous. She stated, *"As far as I know I'm doing everything I can. Nothing more that I can do. It's tough. It's been really tough. Just finding out what I had at first and just dealing with it. I'm just busy, very busy. Now they want me to rest. So I try to rest. Then you have to test your blood sugar two hours after every meal and you can't be resting then."* Her daily life had become highly structured with her activities broken up and bound to set blocks of clocked time. *"I have to eat at a certain time and on schedule. It takes up your whole day. So it's hard to schedule."* During our visit together Ellen stopped our discussion and looked at her watch. She remarked that it's been two hours since she has eaten and it is time to check her blood sugar.

With gestational diabetes her baby's well-being was Ellen's primacy focus. Complying with her prescribed diabetic regime was perceived as her only viable choice to achieve a positive outcome for herself and her baby. *"It's just to have to do what they tell me to do. I want to have a healthy baby and be healthy myself. So I just try to stick to what they're suggesting."* She got through each day by concentrating on her baby's needs and the tasks required in managing her blood sugar. Ellen tried not to dwell on potential adverse consequences gestational diabetes had on her pregnancy and unborn child. *"Oh well, because of the baby it's what you have to do. Just try to stick to what they're suggesting. You just try and take it one day at a time and try not to worry about it."*

Once she started on insulin Ellen found her blood sugar values became less extreme. Similar to other women, as the weeks went and she became more knowledgeable about diabetes, diabetic self-care became a routine part of her daily life. Associated with this shift from the unfamiliar to the familiar Ellen recaptured her sense of control. *"The first time it was all uncertain and unknown. Now it's getting more familiar and slowly controlled. As bad as it seems it does get better. It's very hard to deal with but things are getting better. The blood sugars are where they are supposed to be so I feel better. It's part of my routine now."* Having blood sugar levels that were within a normal range was indicative that she was in control of her situation and as a result life was getting better.

Ellen was induced at 40 weeks gestation and vaginally delivered a healthy baby boy weighing 7 pounds 8 ounces. To Ellen's relief her blood sugar levels had returned to a normal range six weeks later. The aftermath of gestational diabetes for Ellen involved regaining control of her life and daily activities. Monitoring her blood glucose levels was no longer considered a priority. *"I guess I just don't have to be reminded about it all the time. Always checking it. So if it's out of whack, well, I wouldn't know."* She wasn't asked to come back for any follow-up care at the diabetic clinic. Ellen expressed how odd it seemed when the weeks of constant surveillance she had endured came to an abrupt end.

Although her diabetes was resolved after her baby's birth the experience continued to have a lasting impact on Ellen. When we met again after her baby was born Ellen focused on her future health needs and her need to implement strategies to avoid contacting diabetes later in life. She decided to stay on the previously prescribed diabetic diet and maintain the changes to her lifestyle activities. *"Actually the diet I'm trying to stay with. A dietician came to see me and recommended that you try and stick to the 6 meals a day. I've been trying to do that. It's probably a pretty, the healthiest way to eat really. Just to keep my blood sugars regular it doesn't hurt to lose a few pounds either. It wouldn't hurt to lose a few more after so just to, hopefully that we guarantee we don't get this again. Lose a few pounds of weight so I won't ever have to worry about it ever again. So I'm hoping that if I do lose a few pounds it'll stay in check. "* Ellen had once again regained control of her life.

Francine "It's a lot of ups and downs"

This was Francine's second pregnancy, her first having ended the previous year in a miscarriage at ten weeks gestation. Francine mentioned having a thyroid condition that was controlled by medications and was still being closely monitored. Although this pregnancy was unexpected, both Francine and her husband were happy about it. Her first few weeks of pregnancy were uneventful without any noticeable complications. Considering her family history of diabetes and following her doctor's request Francine began to test her fasting blood glucose levels every morning pre-conception and during the early weeks of her pregnancy. It wasn't until she received a positive glucose tolerance test result at twelve weeks gestation that her life suddenly changed. Since acquiring gestational diabetes, Francine described her pregnancy as, *"It's a lot of ups and downs. When I think something is going good I get some bad news. It hasn't gone good."*

Francine had thought her blood sugar levels were at acceptable values and was surprised to discover the contrary. *"I was thinking everything was fine until I had a gestational diabetes test and that was saying that I had it. That was a shock because I was thinking I was doing good because when I was testing myself I was OK. My blood sugars are normal."* How can this be, she felt fine. *"I don't feel any different with this gestational diabetes, the physical, I would never have known without the blood test."* Knowing that she has gestational diabetes Francine reflected upon her earlier pregnancy loss. She was scared of losing this baby too. *"I am thinking I am almost there and to find out I have this risk. It's just a little scary. Now that I know I am afraid. I'm so scared of the effects it's having on my baby. I was just upset. I am crying to my husband and he didn't know what to do. 'cause I've lost a baby once and I don't want to go through it again. And that's what's scary."*

Francine began to question why. Having diabetes can't be true she thought as she searched for probable causes. *"Maybe it's because they made me drink all that sugar. 'Could that be why my numbers were so high? It must be wrong.'"* Francine queried if somehow she to blame. Was it something that she did or didn't do? Could she have prevented this from happening? Was she somehow at fault? Was there something fundamentally wrong with her? *"That day when I found out I was in my*

room crying, 'Why? Why? Why me? Why is it always happening?' That's how I felt, 'Why can't I be normal like everyone else.' I think that maybe if I didn't have that chocolate bar or eat sweet things before maybe I wouldn't have this problem now. Or if I could turn back time and done something different this gestational diabetes wouldn't be there. Maybe if I was healthier I would have had a lower chance of getting gestational diabetes." Francine concluded that her past behaviors probably had a significant role in why she had developed gestational diabetes. She held herself primarily responsible for what has happened.

Francine was referred to the diabetic clinic, an experience she described as *"really scary. All the information that you receive. It's all thrown at you at once."* Following that first visit to the diabetic clinic Francine decided to immediately start managing her diabetes. *"I went grocery shopping that same day. Bought all the healthy stuff and the foods that are good for me and started my diet the next day."* As she became more knowledgeable about diabetes and its management her fears subsided.

Initially Francine was able to manage her diabetes by diet alone. She tested her blood sugar levels for two weeks before her next doctor's appointment. The erratic nature of her blood sugar level and the possible ramifications for self and her baby proved worrisome. *"When I go for my test two hours after each meal I'm so afraid that if it goes past the limit, 'Oh no! What does that mean?* Francine was afraid that she might need insulin as she had previously been told that was a possibility. *"Am I gonna go on insulin?"* she wonders when her blood sugars results were high. *"Sometimes when before I eat, my blood sugar's low, lower than the range and then when I do eat it seems highest. 'Oh what's safe?' If I eat the same thing daily one day it's normal. One day it's not. Who's to say? Like I don't know."* Her blood sugars became unpredictable and unrelated to anything that she tried to do through diet. Her endeavor to control her blood sugar levels became ineffective and frustrating. After a couple of weeks of only diet control Francine required insulin to lower and stabilize her blood sugar levels.

For the remainder of her pregnancy Francine continued managing her diabetes with diet control and insulin therapy. She struggled to achieve and maintain normal

blood sugars, feeling an endless helplessness in her efforts. She questioned her own actions and sought explanations for her inability to control of her blood sugar. *"Even though I was trying to control my blood sugars I really feel like it was controlling me. I'd feel like I was doing, taking my insulin or checking my blood and it would still be high and I'd like, 'Well, why? I'm doing everything right. Why is this happening?' I didn't understand it. I haven't eaten anything sweet. I didn't do this. I didn't do that. But it is still high. Why?"*

Francine's husband, her family and close friends expressed concern for her and the baby throughout the pregnancy and the following weeks after delivery. In an effort to help they lectured Francine about diabetic care and monitored her daily activities. Although Francine considered their actions as supportive she felt they lacked knowledge and understanding about gestational diabetes and what it meant for her and her baby. *"They're worried but they just tell me, 'Don't do this and don't do that. Don't eat sweets.' I know they are trying to look out for me but it seemed like everybody's telling me what to do or what to eat and be careful. They don't really know much about it. I tell them but they've been supportive. My Dad went from phoning once every two weeks or once every week to now two times a week just to check up on me. It makes me happy."* At times she became confrontational with them saying, *"'No, it's me. It's my life. If I want to run it don't tell me what to do.'"*

Throughout her pregnancy Francine worried about her baby, valuing any evidence she could obtain about its wellbeing. Feeling responsible for her unborn baby's health meant Francine felt she had no choice but to follow her prescribed diabetic regime. *"I'm just trying to do it. Live with it. I have to. I have a baby coming. I want to stick to monitoring the sugars."* Her uncertainties about the baby's wellbeing wouldn't be resolved until after the birth. To prevent feeling overwhelmed, Francine concentrated on the present to manage her diabetes, going one step at a time. She thinks about her baby and gains reassurance from its movements, encouraged that all is well. *"I'm just living with it day-by-day, trying to do my best but I just don't know how good I'm doing or what effect it's really gonna have until the baby's born. When my blood sugar shows high I get all worried and then the baby will move. It's just like a gentle reminder that it's there and it just brings my mood and changes it. It*

makes me happy. I know that this is mine inside me and that's what I have to look forward to." Francine tried to stay hopeful and put trust in what she was doing regarding diabetes self-management. *"If I follow my diet, if I monitor myself everything should be OK. Not 100% but still I think of other women who've had this and their baby's have turned out all right."*

Being asymptomatic was an additional concern as Francine was unable to rely on specific physical symptoms to tell her if something is wrong. Living with gestational diabetes was associated with uncertainties leading Francine to experience further fears. *"I just don't feel physically different. I don't feel it's affecting me as much as it would the baby. That's where I'm scared. But mentally it's having an affect on me. Will I have it after the baby's born 'cause they say that you will. It usually goes away after you have the baby. I'm going to look after myself, look after the baby, and I don't know what all the affects are."* Monitoring her blood glucose levels provided the feedback she needed to verify that her efforts have paid off. She judged herself as "doing good" if her actions kept her blood sugar at acceptable levels.

Managing her gestational diabetes was hard work and time-consuming. Time was needed to schedule meals, perform blood testing, and self-inject insulin. Not being able to eat certain foods increased Francine's cravings and tested her self-control and restraint. *"It's like the stuff that I crave. 'Oh I want it but I can't have it!' And that stuff or see somebody or something that I want. Ice cream or the ice cream man will go by and, 'I want an ice cream!' "*

By the end of her pregnancy Francine was tired of following her diabetic routine and just wanted to have her baby. Two weeks prior to delivery her blood pressure increased and a stress test was performed. Although Francine went into spontaneous labor a cesarean section was eventually performed due to fetal distress. Francine delivered a healthy baby boy who weighed 5 pounds 14 ounces at birth. The diabetes had resolved by six weeks postpartum however concern about her future health and whether she will eventually have permanent diabetes lingered in her thoughts. She thought about ways to prevent diabetes. *"So now I'm making sure that I 'm more healthier. That's my plan."* Francine expressed reluctance in becoming

pregnant again. Diabetes might return. *"It's an experience that I won't forget. I'm worried about,... I'm reluctant to get pregnant again. Just the fact of getting it again."*

Gretchen "All of a sudden you're given a challenge"

Gretchen was well into the third trimester of her third pregnancy when we met in her home. She had been diagnosed with gestational diabetes when she went for a routine glucose tolerance test at 31 weeks. Gretchen knew about diabetes, the symptoms and its management from her previous nursing education and the fact her mother who had Type II diabetes. Prior to undergoing her glucose tolerance test Gretchen noted she had been drinking water more at night and was always tired. Although she knew these symptoms were possible indicators of diabetes Gretchen dismissed them, thinking, *"I just thought it was part of the pregnancy. I knew I was at risk because of my mother. I always held it in the back of my mind but I never thought it would happen. I didn't think I had it because I didn't with the other two so it was really quite a shock when I found out."* Diabetes had a stigma attached; you are unwell. Gretchen recognized that her chances of developing diabetes later in life had just increased. *You don't want to get it; it's kind of a taboo thing. It did upset me quite a bit because it does increase your risks for later on in life."*

After her diagnosis Gretchen attended the diabetic clinic for follow-up care, teaching and counseling. She was scared for her baby's wellbeing, stating, *"I know what diabetes has done to my mom. But I don't know how it will affect my child growing inside of me."* With this pregnancy, Gretchen embarked on what she described as, *"an emotional roller coaster. It's been very emotional for me. Especially when you have a hard time controlling. It's nice to know I'm not the only one out there having problems sticking to my diet."* Gretchen described making the prescribed diet adjustments as *"...so restricted. Hard to take for how strict you are. You are put on a diet. It's really hard to follow. It's difficult to get the right proportions and reading all the ingredients. They taught us a little bit about it when I first got my glucometer and the diet. They showed us how to read labels and how to calculate your carbohydrates and that so it's kind of frustrating."*

In consultation with a dietician at the clinic Gretchen was placed on a diabetic diet that she found restrictive and difficult to follow. *"You want to be in control but*

basically you're forced into this diet and you've got to follow it or else you're going to have to deal with the consequences. A big baby." She needed *"... a lot of willpower. You had to control yourself, not to do certain things and to stick to the diet."* Dealing with her cravings and constant hunger became a constant struggle. *"It's kind of frustrating for me because I like my sweets.* She had to be careful what and how much she ate. *Now that I've got to watch my diet I feel hungry all the time. Now that I have to watch my diet I can never, I can't eat as much as I like any more and all my portions I found that almost halved. I am probably losing weight now. Like even though you feel hungry you could eat a few more potatoes,...I love my potatoes and I stay away from them completely! I just eat rice. You can eat a little more rice than potatoes. It is tough to control quantity when you love it so much!"*

When Gretchen went out with her friends or attended family gatherings, to enjoy the social event she made minor adjustments to her diet. *"Those are usually times that I would allow myself to splurge slightly."* She would justify her diet infractions and later dealt with her frustration when these actions adversely affected her blood sugar levels. *"The other day my sister had us over for cake and her cakes are just to die for. So I tried to restrict myself to just one little piece. I made it for my snack. I would have the meal and I waited two hours after to be able to have a dessert with them. I thought at least I could do that. Of course, there's a piece left two and a half hours later. So I had two pieces and my sugar level was pretty high that night. I was very mad at myself that I did that but I thought, 'Well once in a while's not going to hurt.' We don't go out that often. Once in while you really have to control that."*

Until her baby's birth, Gretchen continually monitored and recorded her blood glucose levels to determine if her blood sugar levels stayed within the recommended range. Blood glucose monitoring was a means for her to feel in control of the situation. Knowing her blood sugar levels gave Gretchen the feedback she needed on how well she was managing her diabetes. Although at times encouraging extreme blood sugar level were disheartening. Feelings of guilt were associated with any abnormal blood sugars and attributed to her inability to control them. *"I have to do the blood glucose and everything and test my blood every four times a day. I don't mind doing that. I actually look forward to seeing what my reading is gonna be ... but*

it gets pretty depressing when it's pretty high. The nurses make you feel so guilty. 'How come it is so high!' " Similar to other the women Gretchen felt somehow at fault.

Gretchen described the patronizing nature of one encounter with her doctor, *"he came on me really hard about watching my sugars. You've heard it so many times, ' You've got to watch it or else the baby's going to get big.' You've heard that story all the time and it's just frustrating when you've tried so hard and your doctor's saying, 'You're not doing very good.' They put a lot of guilt on me if you weren't right on. The doctors pretty much express that when you show them the book. They put the pressure on you. This is what happens, if you eat too much sugar. The sugar spills into your blood and goes right to your baby and the baby takes in so much sugar. You could have a larger baby and also possibly a hypoglycemic baby. And all sorts of complications that go with that."*

At 34 weeks gestation her baby was estimated by ultrasound to weigh between 4 to 8 pounds. Gretchen wasn't alarmed by this but faced opposing reactions from health professionals. *"They say, 'You've REALLY got to stick to your diet.' And even though they say if you're gestational diabetic, even a diabetic sticks to their diet, takes their insulin, it still doesn't guarantee their baby's not gonna be big. They make you do all this work. It feels like it's for nothing."* Is all this effort worth it? Will it really make a difference to her baby's size Gretchen questioned?

The physician had warned Gretchen that she might require insulin if her blood sugar levels continued to climb. The prospect of having to self-administer insulin placed additional pressure on Gretchen to control her blood sugar levels. *"Wow! If I don't control it then that's what gonna happen. I really didn't want it to happen but if that's what they had to do then that's what they had to do."* She acknowledged the plausibility of self-administering insulin and her need to adapt. *"I don't really like the idea of taking insulin. It scares me because I don't really want to. It's bad enough pricking your finger for blood. It's kind of hard to just sit there and punch that needle into your finger. I just can't understand what it would be like to have to give yourself insulin too. The actual injection is what scares me."*

When she encountered high blood glucose readings like many other mothers she questioned why? Was there something she did or didn't do? Was she somehow to blame? Was she a failure? *"It's kind of a let-down. Like what did I do? Did I eat something wrong? You are just trying to follow this diet so strictly and its' kind of hard when you've tried. Maybe it's just not watching close enough what I take in."* Gretchen acknowledged that perhaps she still eats more than was recommended on her diet plan and as a consequence her blood sugars readings were too high. *"At supper I was regularly higher. Quite often I was over. I just think it's because I was taking too much at the time. My diet was telling me to take that much but somehow I always seemed to go over."* Gretchen considered that the limited time she had to learn about and adapt to her diabetic diet plan may have been a contributing factor for the difficulties she was experiencing following her diet. *"I'm sure if I had given it another couple of weeks I would have had control of it. But it's kinda hard to learn that quickly. Like during pregnancy it's such a small amount of time. And to learn how your body reacts to different foods."*

Gretchen realized that diet control was only one component of managing her diabetes. *"I could eat the exact same things day after day and I would think my blood sugars are still dropping down and that's when you realize it's not just your diet that you need to control. You need to do other things. Either exercise or reduce stress."* She continued to work for most of her pregnancy and scheduled blood testing around her breaks. Since developing gestational diabetes Gretchen's day to day activities had became very scheduled and time consuming. *"You have so many appointments. There's an obstetrician appointment. There's your diabetic doctors and your ultrasounds and with a busy life it's hard to fit it all in. It takes a lot of scheduling."*

Gretchen's pregnancy continued to term without any need for insulin therapy. Her physician was concerned with the baby's size resulting in Gretchen being induced one week prior to her due date. After a short labor Gretchen vaginally delivered a healthy 9 pound 10 ounce baby boy. She was relieved to find that she no longer needed to monitor her blood sugar as the gestational diabetes had gone. *"You're free! You don't have to worry anymore."*

Experiencing gestational diabetes came as a revelation to Gretchen compelling her to think about her future health and health behaviors. *"Once you have it you can't get rid of it."* Gestational diabetes was not only a learning experience but acted as a stimulus for Gretchen to take preventive measures to avoid diabetes later in life. Life with diabetes for Gretchen meant to many sacrifices, especially around diet. *"It's sure woke me up to the reality of diabetes. It does put me on track for losing weight, to keep my weight down and keep in shape. That way I was able to control my emotions a little bit better and give myself some incentive that I'm not going to let it take me. I'm not going to get diabetes when I'm older. I'm not. I don't want to have to take insulin. I don't want to have to watch what I eat every day. If I want to splurge one day, I want to have cake on my birthday. I don't want to have to worry about taking a piece of cake."*

Gretchen had discovered new ways to eat a healthy diet. *"I'm a little more aware of things, fats and things, of foods. I'm a lot more aware of the quantities I should have if I want to loss weight. I don't have to starve myself to lose it. I just have to eat a regular diet and not overeat."* She continued with the exercise program that she had started during her pregnancy. Although her blood sugars had returned to within a normal range Gretchen planned to have her sugars tested on an annual basis.

Helen "Be proactive; take charge of what's your health"

When she was 24 weeks pregnant with her first child Helen was asked to get a prenatal blood glucose-screening test performed at one of the local labs. She procrastinated for about a week, leaving the requisition in her purse. An article that Helen had read about diabetes in pregnancy presented the view that gestational diabetes was not as a great concern for expectant mothers and babies as some have led us to believe. She was appalled by this message and advocated that undergoing prenatal blood glucose screening is part of a being responsible mother and ensuring the best outcome for your unborn child. *"It's a good thing because we want to have a healthy baby. To have a good outcome."* Helen knew the test was important and that she would have to go eventually and felt guilty for not having it done earlier. She questioned whether her waiting delayed needed treatment and caused harm to her baby.

There was always a potential for her to develop gestational diabetes Helen told me since both her father and twin sister had diabetes. She identified her other risk factors, such as, becoming pregnant in her early thirties and being overweight for most of her adult life. As a precautionary measure Helen began checking her blood sugars on her own early in her pregnancy and thought her results were fine. Thinking about her risk factors she inquired about being screened for diabetes at 20 weeks but Helen's doctor told her that a routine screening test would be scheduled at a later date.

She finally went for her glucose tolerance test at 26 weeks thinking and hoping that, "*'Oh, oh, maybe it'll be OK. But it wasn't.*" Although Helen had previously acknowledged that acquiring gestational diabetes was a possibility she was shocked to learn that she actually had. Two weeks after being diagnosed Helen had her first scheduled appointment at the diabetic clinic for teaching, counseling and follow-up medical care. It was stressful time waiting, without any instructions about her diet, but Helen drew from her nursing background and spoke to her sister to obtain information regarding diabetes, diet and what to do. She ate a sensible diet, continued to monitor her blood sugars, and read as much as she could about diabetes. Helen's discovery of the effects that diabetes could have on her baby was worrisome.

She began testing her blood sugars and based on their results concluded that she was managing well. Her perception of what was good glycemic control drastically changed once she saw her doctor. When she was told how stringent they wanted the blood sugars controlled she soon realized that she hadn't been doing very well at all. The next shock came when Helen was told that in addition to following a strict diet she immediately needed to start on insulin. Requiring insulin was described as a *"a crisis."* The first few days adjusting to her diet and insulin requirements were difficult. *"Actually they didn't give me enough to eat that first week and I lost about 5 pounds. That was really hard. I was starving. I didn't know I could eat in the nighttime."*

The diabetic clinic served as a place where Helen felt that she was being looked after, supported and her diabetes carefully monitored. *" I just felt like everything was being done that had to be done. It took some of the worry away. I was grateful going there. I felt that now I was being looked after, like not being left out in*

the cold. So it wasn't a big anxious time going there. I felt I'd had a good rapport with Dr. T too. We clicked too. He was nice. He's just very objective and just non-judgmental. I was grateful for all the resources and we were well looked after." Feeling her baby's movements and having extra ultrasounds were *"reassuring"* as they gave her the opportunity *"to see that the baby's developing normally and it's not too big."*

By self-monitoring her blood sugar levels, following her recommended diet and having regular doctor appointments Helen became actively involved in managing her diabetes and felt a heightened sense of control. She was not a passive bystander in managing her diabetes and decided to take control by following the strict regime and remaining cognizant of her body's responses to her actions. *"I find monitoring really helpful because I just feel more in control when I know what's going on. You know your blood glucose. You know how much you should have. It's easy to feel that way if your disease is well managed. You have an active role and you can take charge of what's going on. Rather than just roll along. That if I do X, X and X that things will work out. And they have. That your body will respond."* She had discovered some predictability in her actions and associated bodily reactions. She took control of her situation not only for her own health but more importantly 'for the sake of the baby'. Helen spoke of her responsibility for her baby's welfare, as her unborn child is dependent on her. *"It doesn't really affect him unless I don't control myself but if I eat well and if it's well controlled he's not going to be as high-risk for it. It's worth it for sure."*

As her pregnancy progressed Helen internalized aspects of her diabetic regime and by acquiring a familiarity to it allowed herself some flexibility in its management. *"When I was first diagnosed I was really strict about my diet. I measured everything to the letter, which is good, because it gave me a sense of control. Now it feels more routine and sometimes I think I'm not following it as strictly but I think it's just that it's become more familiar. But my motivation's high because I really wanted this baby that's coming. So it's a good thing."* By the end of her pregnancy Helen acquired an increased self-competence in her ability to manage her diabetes. *"It felt good actually to know that I could do this. I feel empowered. Given the information it's like, 'Here,*

you take the ball,' and you run with it." She had the necessary skills and knowledge base to take charge of her life again.

Helen had hoped to go into natural labor but was induced at 40 weeks because of placental insufficiency and increased blood pressure. She vaginally delivered a healthy baby boy who weighed 7 pounds 14 ounces. In the early postpartum Helen was surprised to find how quickly her diabetes had disappeared. Insulin no longer required and she was eating a regular diet the next day. At her six week postpartum check up Helen was relieved to learn that her glucose tolerance test was negative. *"It was just like resolved. It was like 'Boom!'"*

She was relieved to learn that her son was fine and didn't have any problems associated with her diabetes. *"It's a relief. It was a relief to see him. It was all worth it. He was just beautiful and I thought that first week, 'He's not this fat little baby.' It was so important and when I saw that it just validated everything that I did. He was on the 50th percentile for weight and 95th for height. He was thin actually. So it made me feel like I did a good job."*

As Helen reflected back over the past nine months she compared her experience living with diabetes to a grieving process. *"I went through this horrendous time where I was pregnant. So the diabetes, it's like there is no grieving process or whatever. After that it was just over and it was like not an issue. On an emotional level it's like all the Kubler-Ross stages of grieving. I think when you find out that you're diabetic you're in shock. I think after you delivered it was like bargaining 'Why couldn't he have been this way?' And then you just come to accept. Or you're sad about it and then you just come to accept loss. I think that's how it is with diabetes. You just come to accept what's happening and that's what I have to do. You can't change anything that happened. There were a few things that weren't totally ideal but they were well controlled and so it was like essentially a controlled pregnancy."*

Diabetes had a positive impact on Helen as it got her *"in a good place."* She felt healthier than she did before her pregnancy and attributed this feeling to having had diabetes. *"I was eating well through my pregnancy. It's sort of clicked me back into the way I used to eat. It's a new way of eating."* She considered the weight loss she experienced in the first few weeks postpartum were a result of her strict diet.

Having encountered gestational diabetes was also informative and useful for enhancing her health and wellbeing in the future. *"Now I know for sure. It's high-risk to develop diabetes later. I know that I have to be careful because I'm high-risk to get it down the road. But you can't really know. You just do your best. Just be vigilant."*

Irene "I am not a sick person"

Irene was pregnant with her first child when we first met at the diabetic clinic. This pregnancy was a pleasant surprise for both Irene and her husband. She had a history of infertility and been told that the probability for her to ever get pregnant was low.

Irene was in her seventh month of pregnancy when she went for a routine blood glucose-screening test followed by a glucose tolerance test.

Pregnancy was a new experience for Irene and she thought that the fatigue and excessive thirst she had been experiencing was completely normal. Although she had experienced nausea and vomiting early in her pregnancy it had subsided by her third trimester. Irene was shocked at her test results indicating that she had gestational diabetes. She tried to understand why she would have developed diabetes. There had to be a logical explanation because the results did not make sense to her. She recalled, *"One day my doctor found out that my glucose was real high. It shocked me. I said,'What? I didn't even eat any sweets. How come my glucose is very high?' I was very surprised. I am not a sweet girl."*

Irene had already developed high blood pressure with this pregnancy and now to have diabetes meant additional stress. She remembered her doctor mentioning, *"the glucose is getting higher and higher. The baby is getting bigger and bigger. It is very hard for you to deliver."* Irene thought ahead to her delivery fearful and uncertain of the outcome. *"I don't know what it is going to do. I don't know how to come through this. So I am a bit worried whether I will have a hard delivery."* The thought of having gestational diabetes was *"scary". "This is my first baby and it was very hard to have this one too. So I don't want to lose it."* She was scared about miscarrying and wondered about becoming permanently diabetic herself or her baby developing it later.

Irene was referred to a diabetic clinic for further medical care and counseling about managing her diabetes. As part of her diabetes regime she started on a prescribed diet and checked her blood sugar one hour after every meal. She emphasized her need for caution in managing her pregnancy and being *"careful with the baby"*, as she was *"scared of losing it."* To Irene being careful meant, *"Not overdoing something like overeating."* When she once tried having only half a donut her blood sugar level went high. As a result she decided to eliminate all donuts from her diet.

As her pregnancy progressed Irene tried to adapt to her diet and lifestyle restrictions but her efforts were met with frustration. Her freedom was curtailed and her ability to make decisions hampered by others. *"I feel like I cannot do anything that I feel like doing. It's not fun, it's not fun like sometimes you're trying to eat something that you like and you're not allowed to. Sometimes you feel like eating a slice of chocolate and you cannot eat it. 'What is this! I cannot even eat like what I want!' It is little bit frustrating. I eat rice more than the veggie and they told me not to take so much rice because rice has a very high glucose. So I need permission for rice. Whenever I eat I still feel hungry. But the doctor says I better take it once in a while. A small piece at a time for a few times."* At times she felt uncertain of what foods she could safely eat. Will it contain too much sugar? How could she be sure?

At her workplace Irene was concerned the effects her changed eating habit might have on her co-workers' perception of her. She wondered if she would be considered a problem employee. *"I have to take a snack like every half or so, every hour. It seems that I keep eating. It doesn't look good for the boss to keep eating when you are working. It seems like you are not doing your work. You keep eating. It's not very nice for people to see."*

Although Irene found self-monitoring to be helpful, if her blood glucose results were too high or too low her anxiety and concern for her baby's health mounted. Blood glucose monitoring elicited much apprehension regarding the results. Irene sought the rationale for any detected abnormal readings but to no avail. She knew having to self-inject insulin was a possibility if management by diet failed to keep her blood sugars within the recommended range. *"It's good that I check it everyday. But*

it's kind of scary. When you see that if the blood sugar that I found is low I am very happy. If it is over what Dr R wants me to have I am a bit scared. It always happens at breakfast time. The doctor wants me to check it when I get up. It's kind of normal and after I have breakfast. I just take a glass of milk and it goes high. I feel very scared. And then I take lunch it's going down a bit. I take more than the breakfast. I don't understand why. And then sometimes the dinner it is a bit high and sometimes low."

Irene often didn't believe the values that she got especially if they were high. Sometimes Irene considered like cheating when she obtained any high blood sugar results by recording lower values. That way Irene reasoned, it would appear to others that she was managing her diabetes well and people would be less likely to try and control her actions. *"... make it lower so it looks good. Whatever I eat I do feel sometimes to cheat on the blood sugar. That my blood sugar is not that high. So I can, so nobody can control me. Before I go to the doctor I thought of making it lower amount. But something said to me, 'You cannot do that. It's not good for you. So the next time I went to Dr. R I say, 'Is it normal to rise up like that?' It scared me in the first place. You do have those kind of stress to cheating."*

Unfortunately her blood glucose continued to climb as her pregnancy progressed and eventually Irene had to start on insulin injections. She described this event as, *" I hope that I would not get the insulin injection. I feel very bad. I feel very sad."* The thought of giving herself a needle was frightening. *"I have to go through that one for myself. I am so afraid of needles. On the first day my husband tried to help me out. I wouldn't even look at it. I tried to do it myself but I am shaking. Well I say he can't do it for me if I am going to work. I have to do it myself."* Irene wondered what adverse affect insulin could have on her baby, like *"too much medicine inside me."*

With insulin, managing her diabetes suddenly became more complex. She needed to be very time conscious in scheduling her daily routine. *"It's quite difficult. You have to remember when you start having the insulin and after you finish eating for how long and then you have to test your blood. Sometimes I do forget to test the blood. It is kind of hard to keep track if you put all the insulin, the thing that you eat and you didn't test the blood. You don't know if you are eating the right amount even though the same amount if the blood glucose is going up or down."*

To self-inject insulin as part of her diabetic management regime had a negative impact on Irene's self-perception about her general state of health. *"I'm not a sick person. It seems like when I do this it seems like I am on a drug and I am a sick person or whatever."* Irene described having to deal with her co-workers reactions to her self-injecting insulin at her workplace. *"You take lunch. It's work time and you get hungry. You just grab something and you eat. You forget to put in your insulin. I always hear my colleague say, "Come on, come on, have lunch!' I said, "Wait until I have my drug first.' And then I always go to different places for work and the person doesn't know. They thought that I'm really on drug."* Once she explained that she had gestational diabetes and needed to take the insulin people understood. By the end of her pregnancy Irene felt familiar with insulin self-administration and it was less bothersome.

Irene had to cope with the controlling reactions of her husband and other family members as she tried to manage her diabetic diet. *" They say I have too much sickness. It's very hard when they are controlling. It seems like I cannot eat anything. It seems like they keep saying, 'Don't eat too much!' forever. I usually go out with my aunt for coffee or tea. She kind of control me, not to eat this, not to eat that."* Although Irene considered their actions as gestures of caring for her health she characterized it as helpful. She stated, *" they try to help me but sometimes it's very frustrating."*

To justify her actions Irene became assertive in her interactions with family members and continually justified her actions to them. In describing her husband she states, *"He always thought I ate too much food. He knew that I don't really like sweets. I like to buy them and put them in at home and I don't really like to eat them. Only sometimes if you feel like eating them you take one. Whenever he sees me eating something sweet. Just a candy he says, 'You better not eat it!' Sometimes like once a week I go and get some sugar candy and eat. My husband says, 'It's too concentrated. It's directly into your body. It's not good for you.' I say, 'Look at the chart! I give him the chart and see, They say you can take once a day, just one.' He says, ' No.no,no,no!' Well I did, behind him. When he is not around."* Although she felt under the control of others regarding her diet Irene recognized that she was ultimately

responsible for what she ate. *"People can control what you eat. But still you have to control yourself."*

Irene developed high blood pressure late in her pregnancy necessitating an induction at 39 weeks gestation. She had hoped to go into natural labor on her due date, *"But he says no good for the baby and me so I have no choice. I feel that I forced the baby out."* Her labor progressed slowly and Irene eventually underwent a cesarean section. Her son was born healthy with a birth weight of 7 pounds 15 ounces. After delivery her blood glucose level was found to be within the normal range. A blood glucose test repeated a week later had the same results. Irene noticed a number of positive changes for herself after the birth of her baby as a result of her experience with gestational diabetes. She stated, *"Everything changed. It kind of changed my diet, which is very good though. I go for a more healthy diet. And I feel very good than before.* She is free from the surveillance of others. *"Nobody starts to control me anymore. I can eat anything I want."*

Jane "Diabetes is a good thing"

Jane and her husband were expecting their first child after one year of marriage. Trying to maintain an ideal body weight had always been a challenge since her youth Jane informed me. She acknowledged that prior to this pregnancy she ate an unhealthy diet, was overweight and led a fairly sedentary lifestyle. She also knew there was a familial tendency towards diabetes on her father's side. However there weren't any incentives for her to make long-lasting life style changes prior to her pregnancy. Her life experience before pregnancy didn't involve thinking about a baby. Jane didn't really think about what she ate or the adverse effects that her chosen lifestyle might have on her health. That attitude changed as she contemplated having her first child.

"The big change is when I got pregnant. Because like you say, 'Oh, I'll diet next week or next month' or something like that. But when I had a baby I had to go and think. I had to make a decision. It's like for myself and for my baby." She realized that she wasn't alone; there was another entity that she needed to consider when making any decisions regarding her day-to-day activities. Changes needed to be made in how she viewed her health, her previous lifestyle and health behavior.

"That's what it boils down to. So I said either diet of both of us we're not going to be healthy. Because if everybody kept saying, 'Oh you should go on a diet, blah-blah-blah. I said, 'Oh yeah! When I'm ready.' But it wasn't on my mind. I'm not determined to do it. But now I'm more determined. It's when I'm having a baby. Before I didn't care. But now I have ...there's two of us."

Prior to becoming pregnant Jane discovered that her blood sugar levels were high. Her family doctor recommended if she planned to get pregnant that Jane immediately start taking insulin to control her high blood sugar levels. Jane was referred to a diabetic clinic for further testing, counseling and treatment. Although insulin administration was again suggested Jane refused saying that she would *"just slow down and watch what she ate."* Soon after the clinic appointment Jane became pregnant and immediately was started on a diabetic regime that consisted of a restricted diet and insulin therapy.

Jane's diabetes management was centered on adjusting her diet and eating habits. Increasing her awareness of the foods she ate gained precedence. In contrast to her pre-pregnant state, Jane stressed the timing of her meals as well as the type and quantity of food that she ate. *" In the beginning it didn't really bother me but after awhile you really have to watch what you eat. Certain times you have to eat something or else your sugar will go down or go up so it was kind of hard. Before I didn't have to worry about what I ate, I didn't even read the labels of what I ate. Now I have to watch, 'OK, lots of sugar. I can't eat this.' We could go to McDonald's and eat what I usually eat. Now I can't. I could go there but I could just eat like three sticks of french fries. I could do that. I could still eat but I really have to watch what I eat. I have to drink diet Coke but it's in a small portion. I have to slow down on what I eat."* She emphasized her need to closely watch her diet.

For Jane making the required changes to her diet and lifestyle did not come easy. *"You have to force yourself. You have to force yourself."* The felt presence of her baby movements helped Jane adherence to her diabetic regime. Being kicked by her baby was a reminder of her moral responsibility to do no harm to her unborn child. She concluded there wasn't an alternate choice in this situation. *"You have to,*

... I had to do it. I have to think of not my own self but the baby and my own health too."

If she chose to disregard her responsibility to her unborn child by not complying Jane wondered how that reflects on her self-image of being a good mother. She stated, *"I'm trying to be a good mom, if there is danger try and stay away different things that you not supposed to do while you are pregnant. It's not nature. It's you. You're doing it. There are times that I am bad. Like, 'I'm gonna eat this?" But we had to monitor what we do all the time. I can't lie because you can't cheat. If you're cheating yourself it is gonna cost you at the end."* As her pregnancy progressed she questioned what affect her actions would have on her unborn child.

Taking control of managing her pregnancy and gestational diabetes was simply a matter of Jane making the choice to act. She couldn't turn back to her pre-pregnant state. Her baby's welfare depended on what she did or didn't do. *"I didn't really have a choice but then you have to make a choice for your sake. There's only one choice, to follow that certain choice. For me I like that. That way I could do it. If I have another alternative then I probably just do the other. There is no other way. If I don't to it I will be in big trouble. There's no choice here. I liked for them to tell me like that. Then that way I would work really hard. Because I tried dieting before. I tried this but it didn't work out. There's no motivation."* As Jane gained more experience living with her diabetes its management became internalized and an element of her being. The activities involved in her diabetic self-care were absorbed into her daily routine. *"I found that in the beginning it was hard but once you get used to it it's not hard anymore. It's like daily routine."*

Although testing her blood glucose levels at regular intervals was viewed as " *for my own good"* scheduling the testing at work proved problematic particularly at her workplace. Where she could keep her diabetic supplies and taking breaks to test her blood glucose were pressing issues to overcome. Her co-workers were not always supportive of her special needs regarding diabetes self-care and required explanations. *"At lunchtime, before lunch and after lunch I have to test myself. At work I have to get back five minutes early because I have to test my blood. They don't*

understand that sometimes. Then I try to explain it to them and then they understand better."

Jane continued attending the diabetic clinic to monitor the progress of her pregnancy. Her visits were coupled with a certain uneasiness and self-doubt. Was she going to be judged on how her ability to manage her blood súgars since the last visit? Will they find something wrong? Although these visits had an evaluative connotation Jane found them helpful and a means to know that everything was fine and to validate that she was effectively managing her diabetes. *"Every time I go there I'm scared. Ok, what's he gonna say to me? Am I doing good or everything is doing ok? I know that I'm trying my best but I don't want to be disappointed when I go there. I want him to tell me that everything's OK. That if I'm trying my best I want the result. When I know it's high I watch it, really watch it. I say, 'Maybe I eat too much of that.' And I will write that down and Dr. R will say, 'What did you eat?' I said, 'Oh, I ate too much!'"* Jane tries to do her best at managing her diabetes but it seems that it was never be good enough for the diabetic team.

Being under constant surveillance and control by self and others was described troublesome but needed. Jane laments, *"That was the hardest part. But if you think about it, it's for your own good. Everything will be OK. But in the beginning I was really frustrated because I couldn't eat what I wanted to eat."* Jane described a dichotomy where her perception of being constrained was a negative experience but from a positive viewpoint being controlled can lead to a healthy baby making her diabetes management palpable. She was motivated to alter long standing habits.

Jane needed the support of family members and health professionals during her initial struggle adapting to the diabetic diet regime. They were her cheerleaders. *"They were really good. They were really supportive. One time I was really frustrated because I didn't know how to follow a diet even though they're telling me to do certain diets. In the beginning I couldn't do it and then they went, 'Oh, you'll get it. You'll do it."*

Jane remained on insulin therapy and diet control for her entire pregnancy. She was induced three days past her due date and vaginally delivered a healthy baby

girl. Although she had been told to expect a 9 to 10 pound baby her daughter weighed only 7 pounds 11 ounces. Six weeks after giving birth Jane discovered that her diabetes had resolved itself. In her conversation with me after the birth of her daughter, Jane talked about the tremendous relief she felt. *"I was really happy that I wasn't diabetic anymore. I didn't have to worry about injecting myself, checking my blood, and most of all it's really expensive for the strip and stuff."* However she remembers the doctor saying, *"'Well you know what? It is good and bad. You don't have it any more but you have to watch otherwise you will have it.' So it was good. Anyway he gave me motivation again. Like I have set a goal, either not watch it and be diabetic or watch it and not be. I'm choosing the goal of not to have it."*

The knowledge she had gained through managing gestational diabetes during her pregnancy altered Jane's approach to conducting her daily activities. She was more health conscious now and committed to make permanent long- term diet and life style changes. She felt transformed and *"more healthy and more energetic."* If not for her experience with diabetes her life style Jane doubted if the lifestyle changes would have happened. Jane compared her life before gestational diabetes with where she is now. As Jane stated, *"...before I didn't even watch what I eat. I know that I have to read the labels and stuff. To see what are the ingredients. So I am more aware now than before. It's like saved my life or something. For me it's a good thing."*

Jane continued her lifestyle and dietary changes into the postpartum period not solely for her own health but for the sake of her baby's wellbeing as well. With the welfare of her baby on her mind Jane looked forward at her own general health status and declared, *"I'm gonna continue what I'm doing now because I notice a lot of things for myself. I don't want to be sick down the road. Like when I have my kids I can't go with them. I want to be energetic so I can be with them. That's where I want to be. So I'll try for my own sake and for the baby and for my health also. If I want to try to have another one then I'm the one's gonna be suffering so might as well do it now. But in a way I have to get on it. Stick with it. Stick with the diet and everything. I don't want to have diabetes. It's hard."*

Lynne "The baby's the focus"

Lynne was pregnant with her first child when we met at her workplace to talk about her pregnancy experience. Diabetes was in her family background as her mother had Type II diabetes and her older sister had experienced gestational diabetes. Lynne had never thought about developing diabetes herself until she and her husband began thinking about having a baby. She remembers initially dismissing her constant fatigue and yeast infections but based on her nursing background and intuitive knowledge eventually concluded, *"Oh, my god! I have diabetes. I need to see a doctor."* She was upset at the news of having diabetes but *" I knew it was coming. I knew the signs were there."* Initially Lynne questioned the validity of the lab results but once she had acknowledged the reality of diabetes she could deal with her altered pregnancy situation. *"Coming to grips with it is coming to accept it. Ok now I have to accept this so now what do I do with it? I don't think you can do anything about it until you come to grips with it."*

The discovery that her suspicions were true was accompanied with a stark realization of the effect diabetes had on her future plans. *"When you first find out that you have diabetes you know your body's out of control."* Lynne was referred to the diabetic clinic and after further blood glucose tests was immediately put on insulin. *"Oh my god! I can't get pregnant now. I can't have a child now. I have to get this sort of thing under control. Not only am I diabetic, I'm on insulin."*

Lynne chose not to reveal her diabetes to everyone she knew *"because it changes them"* and *"they treat you differently."* Lynne feared being labeled as 'abnormal' stating that diabetes carries a stigma of negativity and shame. Will people accuse her of being unhealthy and a threat to her unborn child? Lynne recalls feeling consoled by her husband's reaction when she told him about her diabetes. *"He looked at me and said, 'I still love you.' I thought, wow, what a perfect thing to say to a woman that just found out she had diabetes. I bet you feel a lot of guilt towards their spouses who they are having this baby with."* Does having diabetes mean that she did something wrong or that she was somehow a different person?

Lynne valued the time she had prior to becoming pregnant and saw it as an opportunity to learn how to effectively manage her diabetes. Adjusting to diabetes

meant focusing on the significant affect that diabetes on her general health rather than denying its existence. *"... part of that adjustment and having to deal with the fact that, 'Oh god, I really have to watch this. I think a lot of diabetics or the ones that I meet live in a certain amount of denial. You don't have a choice. Like I don't think that diabetes is tough to deal with. And I take 4 shots a day. You just do it! And if you feel good there's your positive feedback."* Receiving good care from the diabetic health care team facilitated Lynne's ability to cope.

After her diagnosis Lynne required to make immediate changes to her accustomed lifestyle. The restrictions and controls imposed on her way of life were all encompassing. Lynne used to exercise regularly but found she no longer could without adversely affecting her blood glucose levels. With diabetes management she needed to stay very time conscious and plan every activity to the precise minute. She could no longer take things for granted, for example, making autonomous decisions about what and when she would eat. *" Everything changes when you become diabetic and a controlled diabetic. I had a very strict routine. You have to think about it all the time especially if you are on insulin. Because if you aren't in control you can't go for that hike. You can't do what you normally do. You can't, you don't do things spontaneously. You can't go for wings after work because you've got to think, 'Well, what'd you eat for lunch?' You've got to shop differently. You have to plan your meals. You have to think about what you are going to do today. If I am going out for supper at 8 o'clock with family or friends, I'm eating lunch at 2:30. I'm snacking lots because I'm taking my insulin at 2:30. I'm going to take it again before supper so I snack to maintain my hunger. You just can't eat when you are hungry. You have to plan a meal around a certain time."*

Blood glucose levels and insulin became influential factors related to Lynne's daily eating patterns and activity levels. *"You have to think about your blood sugar all day long. And if you don't it's going to remind you. You're not eating because you are hungry you're eating for your blood sugar. I'm taking my blood sugars to see what I can eat. If you think about it that can make anyone cry."* Once on vacation prior to her pregnancy Lynn went swimming as she had done numerous times in the past. This time she suddenly felt weak and as she looked at the boat in the distance she

immediately questioned the time and amount she last ate. She knew that she wasn't out of shape but her blood sugars had dropped. Having diabetes meant she couldn't be impulsive and do something without advanced careful planning. *"It's very hard to think that you have to live like that. Most of us don't eat every 2 hours. Your sugars need to be written down because only then do you see the trends."*

Effectively maintaining her blood sugars within the prescribed range offered Lynne a sense of control of her body. *"it gives you some power over it because you have to control your blood sugars. I controlled my blood sugars between 3 and 5 before I was pregnant and now I'm 4 to 6 so if I keep them there you're under control."* As the weeks went by following her diagnosis, Lynne became less obsessive about strictly adhering to her diabetic regime. She became attuned with her physical reactions associated hyper- or hypoglycemia which resulted in her knowing what she needed to do to stay in control.

When Lynne became pregnant about four months later she encountered tremendous change once again. *"You become pregnant and then everything changes. Your appetite changes. Like you aren't hungry anymore and then the initial part of pregnancy you don't require a lot of insulin. The last few weeks is when my pregnancy's affecting my diabetes and it's driving me crazy. All of a sudden my sugars are starting to go up. I'm increasing my insulin everyday. I'm having to get much more stricter what I'm eating, when I'm eating it.. I'm taking my sugars 6 to 8 times a day. So it's very difficult."* She started to question her competency in managing her diabetes. *"Like am I doing this right?"* she asked.

"When you don't feel in control you don't feel able to cope." Lynne felt lost and no longer in tune with her body and her blood sugar levels. *"I always knew what my sugar was. Now I don't know what my sugar is. Normally I feel I start to feel around 3 that I should eat. You really want to be conscious of it because it is harder to control right now. And I don't know if that will continue to get worse or not."* Feelings of uncertainty mounted. She needed to regain control once again.

For the sake of her baby's wellbeing Lynne emphasized her responsibility to get her diabetes under control. Her baby was solely dependent upon her to be safe. *"When you're not pregnant you can risk a bit of wavering of that control because*

you're not hurting anybody but yourself. This is a serious thing. Diabetes is fine for you. We can all take care of our own lives and choose what we want to do for your own body. When you choose to bring another life into it, it changes it. No matter what you have to do the baby's the focus."

Lynne considered her pregnancy to be progressing well until she went for her last biophysical profile late in the third trimester. The results indicated her baby was too small for dates. Although the results of her prenatal tests had been normal throughout her pregnancy her relatively uneventful pregnancy had now became eventful. *"You're diabetic so there's no way this can be normal! You're diabetic. There's no way a 6 pound baby can be normal"* was the message she received from health professionals. Lynne immediately felt like *"the floor being dropped. I went from this calm person to being stressed because of all these tests. I did all I could possibly do. I drove around with the blood pressure machine in my car."* Lynne thinks about what more she could have done to have prevented any complications. *"I could have ate more. That's what you go through. Could I have eaten more. Cause maybe I could have eaten more. I didn't gain a lot of weight. I only gained about 14 pounds. I saw the best doctor I could that I thought could handle me during my pregnancy. I saw an obstetrician. What else can you do? I worked. Maybe I could have went off work. I would have been off work at 22 weeks if that's what would make her healthy."* She was doing the best she could but perhaps it wasn't good enough.

Lynne attended the diabetic clinic for close monitoring for her entire pregnancy. *"No matter what you've done. It's not good enough. You want to do the best you can do with your blood sugars and you are being evaluated by your physician."* Conflicts arose in her interactions with some of the members of the health care team. Lynne recalled telling the dietician about the problems she has with adhering to the prescribed diet she was provided and how she had adjusted it.

Lynne continued to work until a week before her labor and delivery. Her pregnancy ended by a scheduled cesarean section at 39 weeks. Her daughter was born healthy weighing 6 pounds 1 ounce. Although Lynn remained diabetic in the postpartum she described experiencing a sense of *"freedom." "I feel great! It's wonderful to get up and not have to eat right away. I can still mange diabetes without*

eating as soon as I get out of bed. I feel I can do more things. Like I can fluctuate my sugars more. I don't have to worry about when I'm going to eat my next bite of food. I can go to sleep and not worry that my blood sugars too low. Whereas when I was pregnant I very much had my day planned. You don't have to be that strict when you are diabetic. "

Lynne's experience with diabetes had positive outcomes. She learned more about her body and bodily responses. Her diet was healthier with increased fruits and vegetables. Like the others, she experienced certain freedom when the pregnancy ended. But experiencing the lifestyle changes came with a price. *"It's been hard. This pregnancy was really hard. Afterwards it was a little hard but it was worth it."*

Kathryn "It is a full time job"

This final story differs from the previous ones as this particular account describes the pregnancy experience of a woman who has had Type I diabetes for a number of years. I included her story to capture a full description of experiencing diabetes in pregnancy. How does the pregnancy experience unfold for a woman who has lived with diabetes? Are there any shared meanings in the women's lived experiences of pre-gestational diabetes and pregnancy induced diabetes?

Kathryn was diagnosed with insulin dependent diabetes in early adolescence and was now in her thirties. Diabetes and its management was a normal part of Kathryn's everyday life. Kathryn was in her seventh month of her second pregnancy when we first met. In contrast to her first pregnancy four years previously, this pregnancy was planned and both Kathryn and her husband were excited about having a second child.

Her first pregnancy was met with ambivalence; being her first Kathryn wasn't sure what to expect. Unfortunately she encountered many diabetes-related complications, which Kathryn attributed to not being monitored closely enough throughout her pregnancy. It was during the third trimester she developed HELLP a form of severe preeclampsia involving hemolysis, elevated liver enzymes and low platelets. Her first pregnancy ended with an emergency C-section at 32 weeks gestation.

She entered her second pregnancy cognizant of the intense care involved as a result of being diabetic but her desire for another child took precedence to any associated risks. When they began to plan for a second child Kathryn recalled she and her husband being told that the chance of HELLP re-occurring in a subsequent pregnancy was low. It was after she had become pregnant that Kathryn discovered her risk for HELLP was actually high. *"I got pregnant I was asking my OB here if he'd get me some information on it. There were two studies that have been done on it. And one of them there's a 30 or 40 percent chance of re-occurrence. If we had known that then we may not have gone ahead with the second pregnancy."*

Most of her second pregnancy progressed without any indications of HELLP returning. Unfortunately her pregnancy course changed in its latter weeks. Once again Kathryn began to develop the symptoms of HELLP syndrome that necessitated an emergency cesarean section at 36 weeks. Kathryn expressed a sense of comfort associated with the close monitoring she received throughout her second pregnancy. She lived in a large urban center and close to any needed health care facilities. *"This time I've been watched so closely. It's good. It's comforting knowing that anything possibly that could go wrong is monitored and checked and double checked."*

Although the intense monitoring during her pregnancy was welcoming, attending numerous doctors' appointments, increasing her insulin and conducting more frequent blood glucose tests created a strain on Kathryn's ability to follow her usual routine. *"It's virtually impossible when you've got so many doctor's appointments in the middle of the week. But like I said it's nice to know that I am watched so closely too . I know that if anything does go wrong it's gonna be picked up almost as soon as it does go wrong. That's a good thing. Different from the first pregnancy."*

Having her second pregnancy closely monitored eased her worries about the possible re-occurrence of HELLP and provided reassurance about her self and her baby's well-being. *"It's just reassuring. I 'm a little more comfortable myself sitting here knowing that I'm not wondering, 'Is this going wrong?' or 'Is that going wrong?' 'Is the HELLP starting?' or 'Are my platelets dropping?' I know and it's being checked and it's looked after every week. There's Dr. R and Dr. H, they're monitoring*

it really closely and plus the biophysical which will show things that are abnormal. It's reassuring that way. So it's a Catch-22." She knows intensive medical surveillance was needed. However leaving appointments with more lab work to be done after receiving good news about her progress was discouraging. *"It's really sad."*

Pregnancy had dramatically changed all that consisted of her daily diabetic routine. Kathryn described the tremendous changes in her day- to-day activities once she became pregnant as *"too hard"* and *"too difficult."* To express the magnitude of the changes involved when pregnant with diabetes she stated, *"It's unreal. It's unreal! I never imagined that it would be this much work. I knew that it was gonna be somewhat involved but not to this extent. I never realized that it was going to be this much. Like blood work every 2 to 4 days. The endocrinologist I have to see, the dietician, and Dr. R, and Dr. M for the eyes and Dr. H. Like it's just non- stop. It's crazy. It wasn't too bad before because it would be every 3 weeks and it was just Dr. R and Dr. H. Now it's all those people PLUS I have to get an ultrasound, a biophysical done every week on top of it. So it's gone crazy. And then on top of that your diet. I watch my diet anyway but with diabetes and pregnancy you've really got to watch it."*

The lifestyle changes that Kathryn needed to make to ensure optimum outcomes for both herself and her baby were a function of not having any viable alternatives available to her. *" You've got to do it if you want a healthy baby and you want to make sure you're healthy. So you just do it. It's just something that I've got to do. Like there's no sense in complaining about it all the time. It's just something that if I want a healthy baby I have to do this. It's the bottom line."*

Kathryn considered being diabetic and pregnant a full time job. *"It's almost been a job! It's full time occupying your day-to-day life. It's not just something that you have to do because you're pregnant. It's fulltime. It's there constantly. It doesn't go away. So in a sense it's almost like a job. At least with a job you can go home and finish with it at the end of the day. But this it's 24 hours, 24-7."* Managing diabetes took priority over everything else in her life. *"It's difficult. It's not easy. It's very consuming of your life. From the time you find out right up until the baby's born. Everything else is kind of put on hold. Not everything else but a lot of things are kind of pushed to the wayside because you are too busy dealing with doctor appointments*

and blood sugars and blood tests and 24 hour urine collections and …ultrasounds and …"

Diabetes was considered a normal part of Kathryn's life. It was part of her being. She never saw it as a big deal; until she became pregnant. *"Then it's crazy. Like you get adjusted to diabetes so it's part of your life and checking your sugars, 2 or 3 times a day and taking your insulin and then watching your diet. But it's part of your life, everyday life, and then when you get pregnant on top of that and everything actually what you have to do because of your pregnancy is hard. Another adjustment again. To have to test their sugars 5 or 6 times in a day. To have to get up like 2 o'clock in the morning and 5 o'clock in the morning to test your sugars."*

To manage her diabetes effectively while pregnant posed an almost insurmountable challenge that Kathryn had to contend with. *"It's just that it put more, more pressure on me. There was a little more expected involved with watching my blood sugars and monitoring the diabetes. That little extra kinda put it over the top. Like you get used to all that comes with being diabetic and it becomes part of your daily routine. But when you have all of this extra to do on top of it all makes it seem like a mountain."*

During her pregnancy Kathryn was monitored closely by others and often felt under their constant surveillance. *"There's always someone watching you. Because you are there so often and everything's scrutinized so closely. This blood sugar went up here. Why did it go up here? Why is it up there?"* Kathryn spoke about one encounter she had with her doctor when blood sugar values were not within the recommended range. Kathryn tried to normalize the necessary lifestyle changes resulting from her being diabetic and pregnant. She had gone out for dinner with some friends and knowingly ate more than what her recommended diet allowed. Her blood sugars went up but she wasn't particularly concerned. She described it as upsetting that her physician was accusing her of not watching close enough and that she should know better, after all she has been diabetic for awhile. Kathryn states, " *Well you know if I was to do this every single night and/or frequently even and not paying attention or trying I could see a comment like that. But just one night out for supper and I happened to have a little extra. Yes I am pregnant. I do have to live and*

I'm not sitting at home, 'Sorry I can't go out for supper.' She still needed to live a normal life.

She worried about her preschooler developing diabetes in the future. When Kathryn noticed that her daughter was constantly thirsty she became concerned that her child may be diabetic and began to test her daughter's blood sugar level. Although they were found to be normal concern for her child's health remained in her thoughts. *"I brought her to the doctor and we had her tested. Everything's fine so we've just got to keep an eye on her. It's always there. But you hope and pray that it doesn't affect her."*

Kathryn felt her friends never fully appreciated or understood the magnitude of the changes she had to make while pregnant to manage her diabetes. *"I don't think they really understand it. Kind of like brushing it off as if it was nothing. Like I was over reacting. I had one friend who thought I was obsessed with my pregnancy. I don't think they understand the fact that being a diabetic. They think you are pregnant. Lots of women that are pregnant and have babies. It's an everyday occurrence. It's not a big deal. But it is a bigger deal when you are diabetic. It certainly is."*

Kathryn developed HELLP a few days after our first meeting together. Initially her platelet count had dropped slightly causing no particular concern for her physician. It was the extreme edema in her face and extremities and erratic blood sugar levels that was worrisome. Kathyrn was at the hospital for a routine appointment when *"I just started, just like that in a matter of a minute. I just felt awful. I had a really bad headache come on and my reflexes were all over the place and they just whipped me upstairs to the ICU. I think it was around 7 or 8 o'clock they took me for surgery and did a c-section."* Kathryn remarked upon how quickly she recovered from her pregnancy experience and the birth of her second child. *"At the end I was just so miserable. And once I had the baby and got up from surgery it was amazing when I got home and stop and think, 'My goodness, I can't believe how good I feel compared to what I had felt before!"*

Managing her diabetes changed after the birth of her son. It was no longer perceived as a full time job consuming most daily activities. *" It's not so much now.*

You're still looking after your sugars relatively good but not that close as far as you had to watch it with the pregnancy with the diet. Sometimes I was testing up to 4-5 times a day and adjusting insulin each time and rally concerned if it was over 7 or 8. You are trying to keep it down to a certain level and the fact that it's a little more relaxed now. So you are more flexible. So it's just back to normal, back to normal. Taking 3 shots a day, watching diet, monitoring glucose ...". Kathryn was finally back to living her normal routine.

The pregnancy experience as depicted in Kathryn's story has some semblance to the others. Diabetes was part of Kathryn's person-hood and remained relatively quiescent until she became pregnant. Experiencing diabetes in pregnancy, whether gestational or pre-gestational, is associated with similar characteristics for women.

These women's stories were gathered on an individual basis yet were analyzed to gain an in-depth understanding of the experiencing gestational diabetes. The next chapter is a retelling of these twelve women's stories in an attempt to capture in themes a few aspects of their lived experience of being pregnant and diabetic.

CHAPTER SIX

Revealing the experience of diabetes in pregnancy

The essence or nature of an experience has been adequately described in language when the description re-awakens or shows us the lived meaning or significance of the experience in a fuller or deeper meaning (Van Manen, 1984, p.38).

Being diagnosed with gestational diabetes came as a shock for many of the women and immediately led to fears and anxieties about what might lay ahead for themselves and their fetus. The women now faced a pregnancy filled with heightened uncertainties regarding the health and well-being of both self and their fetus. Concerns emerged about potential harm that might transpire and affect their fetus. They expressed an increased culpability for what happens to their fetus and were motivated to take appropriate actions in managing their diabetes and pregnancy. Adhering to their diabetic regime was not a matter of having a choice but something that they felt morally compelled to do for the sake of the fetus and themselves. The possibility of long term health problems for self and their baby was an additional worry.

Loss of control and being controlled by both external and internal forces were challenges the women had to overcome throughout their experience with gestational diabetes. Activities in their daily routine that had previously been taken for granted or left unquestioned were immediately open for scrutiny by self and others. Their everyday lives became highly structured and closely connected to clocked time. Coupled with control measures imposed upon their daily activities the women encountered an "out of control" body characterized by erratic blood sugar levels often unresponsive to their conscious efforts to self-manage. The women's resignation to follow their prescribed diabetic regime arose from acknowledging the diabetes that in turn facilitated the development of personal knowledge, personal power and expertise in diabetes self-care. The women engaged in a learning process that led to balancing their adaptation to an imposed diabetic regime and fulfillment of their own needs. The experience of gestational diabetes increased the women's awareness about their

future health and associated health risks, transformed them, and acted as a catalyst for them to make long term healthy lifestyle choices for themselves and their family.

As I listened to the women stories, questioned, read, and re-read the transcripts, wrote and re-wrote I attempted to understand the pregnancy experience of each woman, the past, present and that, which lay ahead. Although each of the woman's pregnancy experience is acknowledged as unique, similarities in their storied experience emerged. Common threads intertwined these women's stories and are depicted through some shared themes. Together these four themes captured the essence of the women's lived experience of gestational diabetes: living a controlled pregnancy, balancing, being the responsible mother, and being transformed. The next section is a detailed discussion of each theme.

THEME I Living a controlled pregnancy

"I think my biggest concern with it at first was a control issue. It's hard on you because I'm used to being in control" (Ellen).

"Control" was a prevalent concept that permeated the pregnancy experience of the women informants. Until she developed gestational diabetes Ellen was accustomed to acting independently and feeling in control of her life and the events around her. Ellen's comment reflected a common refrain by the women about the effect gestational diabetes had on their perception of personal control throughout their pregnancy experience. Encountering diabetes during their pregnancy limited the women's ability to be autonomous beings and remain in control of their normal daily activities. Helen described her childbearing experience as having lived a *"controlled pregnancy."* The accustomed relationships the women had with their pregnant bodies and other entities in their external environment were suddenly disrupted and altered, disturbing their sense of well-being. The theme, "living a controlled pregnancy" encompasses the women's feelings a loss of personal control and being controlled. With the diagnosis of diabetes their ability to act freely was diminished and they became subject to authoritarian measures. The agency of the women was undermined as their self, body and pregnancy became subject to the control and/or

surveillance by both internal and external forces. Their bodies acted as separate adversarial agents and were often resistant to any attempts by the women to manage their diabetes and control their blood sugar levels.

Gestational diabetes silently revealed itself and the women were left to make meaning of a pregnancy complication that was primarily asymptomatic. Many women expressed shock and disbelief at their diagnosis, as they didn't feel physically sick. The diagnosis was puzzling for many of the women. They assumed that if you had a diagnosis of an illness there should be symptoms. *"When he mentioned that my blood sugar was high. Like I didn't feel any different. I didn't believe him"* (Diane). *"I just don't feel very different with this gestational diabetes, the physical. I would never have known without the blood test"* (Francine). Although some women mentioned having had experienced excessive fatigue, thirst and frequent urination prior to being diagnosed they attributed these symptoms as a normal part of being pregnant.

To develop diabetes while pregnant presented foreign territory for many of the women to encounter, learn about and master. *"You are trying to all through out your pregnancy to take things easy and to do things properly and then all of a sudden you're given another challenge"* (Gretchen). One woman described the initial period of adjustment to the change in her pregnancy course as " a crisis." Many tried to rationalize the situation they found themselves in. Associating diabetes with having consumed foods with a high sugar content, some women reflected back on their past eating habits and were perplexed. They hadn't eaten a lot of sweets so why did this happen to them? Others resorted to thoughts of self-blame and confessed that maybe they had been a bit overweight in the past or had poor eating habits. Although some women acknowledged having a familial tendency towards having diabetes, many didn't expect it or hoped it wouldn't happen to them. Women who had experienced gestational diabetes in a previous pregnancy knew of the risk to self and baby and its re-occurrence was disappointing and worrisome.

Loss of control

Pregnancy presents itself as a transition from one state to another, non-pregnant to pregnant to non-pregnant, non-mother to mother, leading a pregnant woman to experience a certain vulnerability with loss of bodily control. I remember

my own pregnant body, its changing shape as I outgrew my clothes and my enlarged abdomen limiting any efforts to easily sit at my desk. Eating my favorite foods was coupled with nausea. Being assessed at risk I became subject to various prenatal tests to monitor my pregnancy progress. I submitted to them because I believed that they would help ensure a healthy outcome for myself and my child. In addition to the fairly predictable bodily changes associated with a normal pregnancy, the women in this study were confronted with new and unfamiliar bodily responses associated with gestational diabetes.

The women's pregnant body now encumbered with diabetes became distinct from the women's self and presented as a problem of taking control over (bodily functions) as well as an entity that needed to be controlled (diabetes). The women experienced a pregnant body they described as no longer under their control or ownership and consequently affected their ability to deal effectively with their diabetes. *"When you don't feel in control you don't feel able to cope"* (Lynne).

The notion of inhabiting their pregnant body with no degree of ownership of it was evident in the women's description of trying to manage their blood sugars. Their body as agent acted independently to what the women consciously did or didn't do to keep their blood sugars levels within a normal range. Their limited success in controlling their blood sugar proved exasperating as blood glucose functioning took on a sense of independence, developing a life of its own. The women experienced a betrayal of trust in their body reactions to any interventions they undertook to control their blood sugar. Frustration mounted as all efforts to control their blood sugars were in vain. *"It was being totally out of my control. There didn't seem to be anything I could do that would help. My own body. It's just not doing what it is supposed to be doing. No matter what I ate, no matter what exercise I did. It just didn't seem to help my blood sugars. They just did whatever they wanted to"* (Ellen). As their bodies became unreliable and immune to any direct actions by the women their sense of loss of bodily control increased.

The unpredictable nature of their blood sugar was particularly difficult for the women to cope with. A tremendous amount of anguish was expressed in the women's attempts to understand what was happening to them and as they tried to control their

blood sugars. *"I'd feel like I was taking my insulin or checking my blood and it would be still be high and I'd like say, 'Well why? I'm doing everything right, why is this happening?' I didn't understand it. I haven't eaten anything sweet. I didn't do this. I didn't do that. But it is still high. Why?"* (Francine). The erratic nature of their glucose levels left the woman feeling uncertain and vulnerable. *"I eat the same thing daily and one day it's normal and one day's it's not. Who's to say? Like I don't know. 'Is it safe to eat?'"* (Francine). Variable blood glucose levels resulted in a lack of faith in the dependability and adaptability of a basic bodily function that the women relied on for a sense of well-being.

Diabetes and its management were all encompassing and transcended the women's mind, body and spirit. At the time of the diagnosis, their pregnancy suddenly changed course influencing the women's sense of priorities, perception of time, space and lived relations with their pregnant body and other people. Lynne spoke of her experience in this way, *"It's not just a disease that affects how you feel when you wake up in the morning, it's a disease that can affect you, affect your life, how you cope with life, it affects your moods."* The increased monitoring and concern by others for her well-being transformed her perception of being a healthy calm individual to one who was sick and stressed. Kathryn had expressed the significance that diabetes had on her daily life. *"It's difficult. It's not easy. It's a full time job. It's very consuming of your life. From the time you find out until the baby is born. And everything else is kind of put on hold."*

As the women shifted their attention to diabetes management their accustomed way of life required re-structuring. Accommodating the various aspects to diabetes care took precedence over everything else that they did. The imposition of a highly structured lifestyle such as scheduling meal and snack times was associated with a loss of spontaneity and altered patterns of living. Lynne who described herself as an avid outdoor type stated, *"Everything changes when you become diabetic. Because if you are not in control, you can't go on that hike. You can't do what you would normally do. You can't do things spontaneously. You can't go for wings after work at Earl's because you've got to think, 'Well, what'd you eat for lunch.'"*

The women described living a regimented lifestyle characterized by heightened attentiveness to their everyday tasks. Advanced planning was needed particularly for meals. *I had to be a little more conscious of what I ate, what I didn't eat and when I had to eat. When you had to do this and when you had to do that. So it was a little more structured"* (Gretchen). The strict adherence to a dietary regime, activity restrictions, intense scheduling, frequent physician appointments and the expense of the diabetic supplies had an immense impact on the women's daily lives. Their daily life activities suddenly become bound and enclosed within strict parameters further limiting their freedom and creating frustration. *"I feel like I cannot do anything that I feel like doing."* (Irene) *"It's horrible! Everything is so strict. You can't do this. You can't do that"* (Cathi).

Distinct segments of lived time, such as, the three trimesters, nine months or forty weeks help characterize a pregnancy's trajectory. Throughout the course of their pregnancy, hourly-lived time was emphasized as the women tried to integrate diabetes care into their daily lives. To effectively follow their diabetic regime the women had to remain cognizant of scheduling their daily activities by the 24-hour clock. Their usual day-to-day tasks were highly structured and aligned closely to specific segments of clocked time. *"It was more just the diet, the lifestyle, the making sure that you were on such a schedule. You got up, you had to eat. You had to do this. You had to do that. You had to make sure you took your insulin and you had to make sure that you were prepared to take the insulin at the proper time and that your food came if you were in a restaurant or if you were at a party"* (Barbara). Organizing their day involved considerable advanced planning and scheduling to meet the demands of diabetes management. *"You have so many appointments to remember. There's an obstetrician appointment, there's your diabetic doctor and your ultrasounds. With a busy life it's hard to fit it all in. It takes a lot of scheduling"* (Gretchen). Daily scheduling became even more complex for those women who required insulin. *"It's quite difficult. You have to remember when do you start having the insulin and after you finish eating for how long and then you have to test your blood"* (Irene).

Restriction and regulation by others of the women's routine daily tasks, particularly pertaining to their diet, were accentuated. Potential adverse effects of the women's diet and dietary habits on maternal and neonatal outcomes had an increased significance for self and others. Family members closely observed and questioned what the women ate or didn't eat throughout the pregnancy. The women developed a heightened awareness of what they consumed, when they ate and how their diet could adversely affect their blood sugar level and unborn child. *"It's kind of hard. Before I didn't have to worry about what I eat. I don't even read the labels of what I eat. Now I have to watch. 'Ok, lots of sugar. I can't eat this'"* (Jane). Earlier pleasures with consuming favorite foods were lost.

The restrictions placed on their customary dietary habits increased the women's cravings for certain foods not permitted on their diet. The prohibition of their favorite foods created emotional distress from the intense desire to eat them. One woman described tolerating her cravings as shear torture. *"I loved sweets but I really didn't have too many sweets. But it seems like with the pregnancy and not being able to have it made me want it more"* (Francine). Cathi in describing her difficulty with her cravings for chocolate states, *"It was awful! Because I really, really wanted it and I knew I couldn't have it. I had to say, 'No! And I really didn't like that.'"* Food had become the forbidden fruit and consequently was always tempting. *"It's tough to control quantity when you love it so much. To stick to the diet. Even though you feel hungry you could eat a few more potatoes. I love my potatoes and I only stick to half of them"* (Gretchen). Gretchen's diet regime means she has to limit consumption of the foods she loves.

Being controlled

The women could no longer live their lives in a "taken for granted" manner, as they needed to be cognizant of causing possible harm to their unborn child. Their regimented lifestyle within a controlled environment was described as being hard and a challenge. Their comments reminded me of a conversation I had with a woman acquaintance at a nursing conference that we were both attending. She had experienced gestational diabetes in her last pregnancy and described her experience with diabetes as having been thrown into a lake and told to swim. She struggled to

take some strokes and stay afloat but noticed as she turned around that her foot was tied to the dock. Her attempts to break away from the rope and swim freely were onerous. Compliance to their diabetic regime was arduous and their struggle to adapt was captured in this woman's swimming metaphor. These women described struggling to manage their diabetes as best they could but their behaviors were constantly under external restraints.

To achieve and maintain normal blood sugar value is a primary goal of diabetes management and as a result their blood sugar remained foremost on the women's minds. In addition to the external control being placed on their actions the women's behaviors were controlled internally by their bodily functions particularly their blood sugar. Blood sugar functioning was personified with authoritative power to control the actions of the women. *"You can't do what you would normally do. You have to think about your blood sugar all day long. And if you don't it's going to remind you"* (Lynne). The women felt controlled by their blood glucose and relied on the values to conduct their daily tasks. *"Even though I was controlling my blood sugars I really felt it was controlling me"* (Francine). They became highly dependent upon on knowing their blood sugar level and considered this knowledge of high priority. *"I'm taking my blood sugars and see if I need to eat. If you think about it that can make anybody cry"* (Lynne).

In following their diabetic regime the women relinquished some personal control over managing their pregnancy to become dependent upon medical care to ensure a safe birth and a healthy baby. The mandate of diabetic control, to achieve a healthy outcome for both mother and baby, perpetuated the women becoming the 'object' body to be subjected to constant scrutiny and surveillance by both self and others. The use of technology to closely monitor themselves and their unborn child became a wanted and legitimate part of the women's pregnancy care. Excerpts from an educational handout *Gestational diabetes: What to expect* (1997) illustrate the support of technological care for pregnant women with diabetes.

> Gestational diabetes mellitus is a disease that requires individualized treatment. The American Diabetic Association strongly encourages women with this disease to seek qualified medical help and to work with their health

> care practitioners to develop a program to manage their specific condition. You can't forget to care for gestational diabetes. Special care is needed to keep you and your baby healthy. The tests we describe are used during all types of pregnancies. But they are particularly helpful in pregnant women with gestational diabetes, because they help your health care team chart your baby's growth. This technology is pretty amazing and quite comforting when you realize that it can increase the chances of having a healthy baby. (p. 9)

The seriousness of gestational diabetes is emphasized with the message that the mother cannot be complacent in diabetes care if she wants her baby and self to be healthy. The word "disease" signifies abnormality associated with the pregnancy and the need for curative measures. The benefits of medical technology in terms of promoting the health and well being of the mother and her child are emphasized.

The following statements from an American Diabetes Association internet publication (1997) regarding gestational diabetes deliver an ominous message regarding the potential outcomes for the baby if the mother does not comply with the recommended management regime. "You are 28 weeks pregnant. Your health care provider has just told you that you have gestational diabetes mellitus. Should you be concerned? The short answer is: Yes. Untreated or poorly controlled gestational diabetes can hurt your baby." A sense of urgency to control gestational diabetes is highlighted in the following excerpt, "Because this condition can hurt you and your baby, you need to start treatment quickly." In the next statement gestational diabetes is put in a different perspective. "While gestational diabetes is a cause for concern, the good news is that you and your health care team work together to lower your high blood sugar levels. And, with this help, you can turn your concern into a healthy pregnancy for you and a healthy start for your baby." It seems though this positive outcome will occur only if the expectant mother chooses to follow her prescribed regime and succumb to externally placed controls.

The emphasis that women placed on their body as 'object' and their dependency upon technology to determine the health and well being of self and baby were at the expense of their own intuition and self-determination. Being closely monitored throughout their pregnancy was reassuring and validated that everything

was progressing in a satisfactory manner. The women talked about their pregnancy being well controlled and looked after. *"They did an extra ultrasound at 32 weeks. That was kind of reassuring. Just to see that the baby's developing normally and it's not too big"* (Helen). *"It was controlled, it's been watched and it's been monitored. It's really been taken care of. So I'm not as concerned because I think it probably has a better chance at being a normal pregnancy"* (Barbara).

Diabetes affected the women's relationships within their family, their workplace, the medical community and social networks. Their interactions with others had become more problematic and intense. The women described conducting day-to-day activities under the relentless scrutiny by other people. Friends, family and health professionals observed and questioned the women about any behaviors that were considered out of the ordinary. There seemed to be nothing in the women's lives that was sacred and free from others' inquisition. As one women noted she constantly had to reveal what she was doing and why to family members even if only to use the washroom. Were the women no longer trusted to keep themselves and their unborn child safe from harm?

Irene describes the surveillance she encountered with hospital staff, *"like the hospital were spying on me, what I eat."* Surveillance is derived from the Latin vigilare meaning watchful or to have close watch kept over a person. Being confronted or questioned about their actions forced the women to exercise their autonomy and justify their behaviors to others. In speaking of her common-law husband Cathi noted, *"He monitors everything! Right down to the little tiny ounce of chocolate I am gonna have. He says, 'You know you are not allowed to have that.' I had to convince him to go to the store the other night to get ice cream for me. And I had to take out my diabetic chart and prove to him that I'm allowed to have a half a cup of ice cream. He's almost fanatic about it. Like if I reach for the salt shaker he's like, 'What are you doing?' I say, ' I just want a little bit of salt.' ' You don't need any!' Like, ' A little bit of salt's ok.' 'No!'"* The concern displayed by other people towards them was judged as strange. *"It's kind of weird when someone is worrying about what you can and can't eat"* (Barbara). Questions arise in terms of whose well-being is of prime concern, the woman's or the unborn child's.

To counteract the control exerted by others some women began to counter the reactions of people towards them by strongly justifying their actions or becoming rebellious and at times defiant. *"Like once a week I go and get sugar candy and my husband says, 'It's too concentrated. It goes directly into your body. Not good for you.' I say, 'Look at the chart and see. They say I can take once a day. Just one.' He say, 'No,no,no,no' Well I did behind him.* (laughing) *When he is not around"* (Irene). Another woman hid chocolates from her husband and ate them when he wasn't at home.

Although friends and family members were described as controlling and overbearing they were also perceived as a key source of support. Francine remarked about her friends, *"I know they are looking out for me but it seemed like everybody's telling me what to do or what to eat, and be careful. And 'No it's me. It's my life if I want to run it, don't tell me what to do.'"* Reflecting upon her reactions to friends' actions Francine stated, *"First I was like, snap! 'I know what I am doing! Just leave,...I know what I am doing!' Then after awhile maybe after I get calm about it. 'Oh, maybe they were right. I shouldn't have that right now.'"* Feelings of self-doubt emerged as they considered the reactions of others to their behaviors. Are their actions really wrong? Will they harm the baby? Although the controlling behavior of friends and family members was a source of frustration at the same time the extra attention was appreciated and viewed by some of women as caring behavior. *"I don't mind. It just shows that he* (husband) *cares"* (Cathi).

Women used terms such *"parole officer"* and *"monitor"* to depict the controlling behaviors of family members. Being a monitor implies there is something that needs to be checked. *"My mother is the best one at that, she was my monitor, she kept nagging, and it was sort of nagging to me. If I didn't follow the diet one meal or something or have an extra piece of whatever. An extra half of potato or something like that. You don't think it's a big splurge but mom would go, 'Now, I don't think you can have that!' It was always something, and just, 'Go away Mom!'"* (Gretchen). Control of the women's behaviors occurred in social settings and continued for some after the baby's birth. *"I usually go out with my aunt for coffee or tea something like that. She kind of controls me, not eat this, not eat that. They say don't eat too much*

chili. Chili is my favorite. I like chili. Even though I have this baby I like chili. They say, 'Don't eat too much chili or it will boost your blood pressure.' Anything I put in my mouth they say, 'Don't eat too much'" (Irene). Many of the women did develop hypertension during their pregnancy a fact that may have reaffirmed others' need to control the women's actions.

Their relationship with health professionals, particularly their physician was a source of both solace and frustration. How they were treated and what was said affected the women's sense of psychological wellbeing. The women's dependency on the care from the health care professionals to ensure positive outcomes for themselves and their baby conflicted with their need to be in control of their lives. Paternalistic overtones were evident in the women's encounters with members of the health care team. Health professionals were the experts in possession of scientific knowledge while the women perceived themselves inferior and unknowledgeable about diabetes and its management. Their personal experience held secondary importance to expert knowledge in the implementation of a diabetic management regime. Some women felt subject to derogatory treatment and described being treated like a child. There was a sense of being told what to do by the health professionals through lecture and threats. *"I felt like I was being chastised like a little girl. 'I told you to go and do this but you didn't do it. Shame on you'"* (Cathi).

Although attending the diabetic clinic was a source of comfort and a means to reveal that they are managing well many women expressed nervousness and a fear of being judged. If their blood sugar was less than satisfactory the women felt guilty of failing to follow their recommended diabetic regime and consequently harming their baby. They felt being reprimanded and accused of not doing what they were told if their blood sugar levels were outside the recommended range. *" ...the nurses made you feel so guilty. How come it's so high?'"* (Gretchen). Was she somehow to blame?

Throughout the pregnancy, the women tried to be vigilant in protecting the self and that of the unborn child from undue harm. They acted on the experiential knowledge gained from dealing with gestational diabetes either during the present or past pregnancies to obtain the care they felt was needed. Cathi described how she

used and acted upon her personal knowledge about diabetes to try and obtain the care that she felt was required. She felt her needs were left unheard. In talking about her doctor she stated, *"I stopped going to him. He was driving me crazy making me feel like I was doing everything wrong. You're not doing this or you're not doing that. I am thinking, 'Ok, are we doing everything by the book or am I gonna follow what my body is telling me.'"*

The labor and delivery experience for many of the women proceeded according to medical directives depriving the women of the childbirth that they had planned and hoped for. The women felt a loss in decision-making power with the only viable choice available to them was to follow the recommended mode of delivery. One woman in describing her induction stated, *"I was disappointed. I wanted a to have regular labor. But I had to"* (Francine).

Closely aligned with the women's experience having loss of control and being controlled was the development of a new relationship with their pregnant bodies. After the initial shock regarding having diabetes the women sought out information to determine the impact of diabetes on their pregnancies, unborn babies and lives. Life with gestational diabetes presented the women with the struggle to acknowledge the reality of diabetes and to gain insight into their strengths and ability to take charge. Encountering gestational diabetes forced the women to find innovative ways to adapt to their pregnancy experience. Their pregnancy experience was characterized as a challenge to regain some control of both internal and external factors that were affecting their well-being. Acquiring relevant information and skills to deal with being pregnant and diabetic was paramount. The second theme, "balancing", illustrates the women's adaptation to their controlled pregnancy through accommodating the imposed diabetic regime into their sense of being and in turn taking charge of managing their diabetes, their lives, and the remainder of the pregnancy process.

THEME II Balancing

"So I just had to just take charge" (Diane)

Loss of a normal pregnancy, bodily control and autonomous decision-making were depicted in the women's experience of being pregnant and diabetic. For many of the women the diagnosis of diabetes came without warning leaving them with increased fears, uncertainty and concern for the welfare of themselves and their baby. *"First it was scary because it was something unknown I guess and new to me"* (Barbara). *"Everything was fine until I had a gestational diabetes test and that was saying that I had it. That was like a shock because I was thinking I was doing good because when I was testing myself I was OK. So it's a little scary. Now that I know I am afraid"* (Helen). The women and their families were prompted to discover innovative ways to cope with the elusive nature of diabetes.

The theme, 'balancing' involves the women's personal struggle and their ability to take charge and overcome the challenges of following a prescribed diabetic regime, being under constant surveillance and adapting to many lifestyle changes. Achieving a balanced sense of control was portrayed as a movement from the point of strict compliance to active self-management of their diabetic pregnancy. They reached a state of equilibrium in their lives when they felt in good diabetic control without having to make additional major sacrifices and further jeopardize their enjoyment of their pregnancy. *"Now I can stop worrying about that and enjoy being pregnant and concentrate on doing what I was doing. Which is taking care of myself and enjoying the pregnancy and just doing what I was doing"* (Diane).

The challenges

Although the women often felt fine physically, meaning that their pregnancy was devoid of any explicit symptoms, they and their fetus were considered "at risk". To gain mastery of their situation and minimize their concerns the women sought to understand what diabetes meant for them and their fetus. Possessing a limited scientific knowledge base from which to draw upon prompted the women to search for relevant information to help them cope. The women consulted relatives, friends and health professionals in addition to seeking published resources about diabetes and its management.

The women described their efforts to assume some control of their lives during their pregnancy as difficult and used metaphors such as it being a *"struggle,*

hard work or a pain." To struggle means to make strenuous efforts against opposition and any progress is made with great difficulty. Encountering diabetes presented an obstacle the women needed to acknowledge, accept and overcome. At the outset the extra demands involved in managing diabetes while pregnant seemed insurmountable. One woman characterized her dealing with diabetes like facing a mountain. Diabetes management forced the women to cope with time pressures, complex scheduling of social gatherings or familial commitments, regimented lifestyle and food temptations. As Gretchen remarked, *"It's hard to take. For how strict you are."*

I am reminded of a friend of mine who recently came for supper at my home. Her eleven year old daughter has been recently been diagnosed with Type I diabetes. My friend and her family have been over for dinner many times in the past but this is first time since her daughter was diagnosed with diabetes mellitus. I sensed the differences in this visit as I was preparing the meal. I reflected upon the women's stories about trying to accommodate their dietary needs with those of others. Her question of when supper would be served was not an idle one but one that really required a definite answer. The question, "When is supper?" was asked with a certain urgency by the mother. It was a comment that I needed to pay attention to. My answer would set in motion by the mother certain activities that were associated with her daughter's blood glucose levels. Later at the table as we finished our meal I overheard the parents discussing the particulars of what their daughter had just eaten. Where on previous occasions we might have engaged in catching up on each other's activities the dinner conversation turned towards the parents discussing numbers of calories, carbohydrates, fats, and proteins that their daughter had just consumed. I thought it interesting, how our conversation seemed so clinical and precise.

Following their diabetic regime was viewed by the women as work and very time-consuming. *"I'm just busy, very busy. I need to lay down and rest but you really can't do that because you've got be up in 2 hours to check your blood"* (Ellen). Kathryn who was pregnant with her second child exclaimed, *"It's unreal. It's unreal. I never imagined that it would be this much work. I knew it was gonna be somewhat involved but not to this extent. I never realized it was going to be this much. Like*

blood work every 2-4 days and the endocriniologist I have to see and the dietician and the doctor for the eyes and the obstetrician. It's non-stop. It's crazy. Now it's all those people plus I have to get an ultrasound and a biophysical done every week on top of that."

Although acknowledged as a necessary component of managing diabetes, the dietary restrictions and stringent meal planning proved challenging and difficult to follow. Frustration arose from having to exercise constraint in their eating habits and endure a loss of eating favorite foods. *"Sometimes you feel like eating just a slice of chocolate and you can not eat it. 'What is this! I cannot eat what I want!' It is kind of a little bit frustrating"* (Irene). Adjusting to both the increased frequency of meals and the smaller portions proved troublesome for some women. *"Now that I have to watch my diet I feel hungry all the time. I can never eat as much as I like anymore. All of my portions I found that almost halved"* (Gretchen). *"I'm eating about 6 times a day. I have never eaten that much in my life"* (Cathi). The scheduling of their meals and snacks was regimented and dependent upon their blood sugar level rather than the physiological symptom of hunger. *"They want you to gain a certain amount of weight and I don't feel hungry. So it's hard to eat all that food. When you are not hungry it feels horrible"* (Ellen).

Trying to undertake unfamiliar and unpleasant medical tasks (glucose monitoring, insulin injections), accommodate the needs of significant others and gain their understanding while adhering to their diabetic regime proved tiring. The need for frequent snacking, insulin injections, blood glucose testing and storage of supplies became problematic for the women at their workplace. Fulfilling their work obligations and accommodating the needs of co-workers while seeking some understanding about the necessity for diabetes management was frustrating. Questions arose concerning where can they safely store diabetic supplies or administer insulin. *"In the beginning I was having a hard time because at lunchtime, before lunch and after lunch I have to test my blood and it is so much bother. At work I have to get back 5 minutes early because I have to take my blood. And they don't understand that sometimes"* (Jane). Adjusting to their diabetic regime influenced the women's interactions with members of their immediate family and external social

groups. The additional preparations and meal planning required to accommodate their dietary needs accentuated their unique situation at social gatherings with friends or family. In response the women were challenged to create a sense of normalcy when attending these functions. They tried to minimize any attention being drawn to them by adjusting their diet plan as inconspicuously as possible.

The reaction of family members and friends to the required dietary changes produced mixed feelings on part of the women. For example, feelings of being supportive and understood by their spouse were hampered with the perception that meeting their dietary needs was bothersome. *"He's pretty good, for the most part. It's 'Honey, I have to eat now.' He'll help me find something. 'Ok, let's find a snack. Let's do this. Let's do that. Ok, Let's grab something. Whatever you need.' Although it's more of an inconvenience kind of thing"* (Barbara).

A stigma surrounded their diabetes created within the women a negative perception of self. Stigma derives from the Latin word 'stigmat', meaning to mark or brand. Stigmatization can lead a person to internalize a sense of self as weak, unworthy and shameful (Kleinman, 1988). One woman described having diabetes as *"taboo"*. Diabetes being a chronic illness didn't fit with the social norm of what is acceptable to be healthy particularly when pregnant. Does having diabetes mean that they are guilty of being unable to have a normal pregnancy and produce a healthy baby? *"Like when you first find out that you are diabetic, you do feel unhealthy, well, you are unhealthy"* (Lynne). Does having diabetes mean that they are ill?

Feelings of embarrassment and guilt related to the women's 'dis'-comfort about having diabetes emerged soon after being diagnosed and led to an increased sensitivity about how others might view and relate to them. Have they changed in some way? Are they still the same person? The women expressed concern about facing negative reactions from family and friends. Guilt was illustrated in Lynne's comments about her husband's reactions to her being diabetic. *"I was with my husband when he found out I was diabetic. I remember the first time I said, 'I have diabetes.' And he looked at me and he said, 'I still love you.' And I thought what a perfect thing to say to a woman that just found out that she had diabetes. What a perfect thing to say. There's a lot of guilt towards their spouses who they are having*

mis baby with" (Lynne). To help minimize the expected negativity associated with diabetes many women initially concealed any evidence of having gestational diabetes from friends and relatives. *"You are so embarrassed that you don't want anyone else to know and you kind of hid it away"* (Barbara). Concerned about how they might be treated they carefully chose who to tell and when. They became self-conscious and feared being stereotyped and labeled by others. *"It's not something that you tell the world. They treat you treat you differently, even physicians. I think people are quick to label you. I think diabetics are normal people. But a lot of people don't"* (Lynne).

Some women were attentive to the negative reactions of others regarding the self-administration of insulin in public settings. The need for insulin injections was described in derogatory terms. Will people consider them drug addicts? *"I can always feel my colleague say, 'Come on, come on, have lunch.' I said, 'Wait until I have my DRUG first'"* (Irene). *"I got funny looks sometime. You almost feel like, 'Oh yeah. You're shooting yourself up in public'"* (Audrey). Barbara talks of her husband's embarrassment with her openness in administering her insulin in open public settings. Should she be running to the public washroom instead?

The need for insulin as part of their diabetic self-care management was something the women wanted to avoid. The actual act of self-injecting insulin by needle to control their blood sugar was stress provoking. Taking any type of medicine during pregnancy is frowned upon and considered potentially harmful to the unborn. Requiring insulin to control their blood sugar indicated that they had failed to successfully control their blood sugar levels and that the diabetes was worsening. *"It was just the matter of just eating and when the numbers started getting really high they're going to have to put me on insulin. It was just a matter of trying to control it as long as you could without the insulin"* (Barbara). Insulin administration was equated to being prescribed a medication and increased the women's concern about potential adverse effects on the unborn baby. A need for insulin reinforced the impression that they were unhealthy. *"When I do this it seems like I am on drugs and I am a sick person. I am scared it might harm the baby. Like too much medication"* (Irene).

Managing their diabetes involved the challenge of the women (self) establishing a balance to keep their diabetes (body) under control and being controlled by others and their body's physiological, psychological and immunological responses. By gaining experience throughout their pregnancy the women acquired a familiarity with their diabetes regime and their perceived ability and strength to re-gain control of their own lives increased. The women developed a personal expertise in the self-management of their diabetes. Experiencing success in achieving adequate blood glucose levels offered the women much needed positive feedback. Through gaining control of their diabetes and pregnancy they acquired a sense of unity between self and body. The women realized that they could overcome the challenges they had initially faced with diabetes care, take control and gain a sense of equilibrium.

Taking control

Conscious efforts were made by the women to accept what had happened to them and regain control of their lives. The integration of diabetes into their lives commenced with accepting the fact that yes they have diabetes. *"I think that's how it is with diabetes. You just come to accept what's happening"* (Helen). Their decision-making was based on taking a position of resignation. Gestational diabetes was placed in the perspective that they had it they couldn't get rid of it, so they might as well *"try and enjoy your pregnancy. Some things you can't control. You've got it, deal with it"* (Barbara).

The women's decision to acknowledge the presence of gestational diabetes, to face the challenges that lay before them, and to assume some control was based on their perception of having limited choices available to them. Choice implies having the opportunity to decide between different alternatives freely and without constraints. A person has choice in decision-making when there are viable alternatives from which to choose. The women were cognizant of their risks for developing diabetes later in life, having a big baby and a difficult delivery. Their final decision on how to best manage their diabetes was dependent upon its consequence for others, particularly for the fetus. *"You're supposed to watch your diet at all times now, but particularly when you are pregnant. With gestational*

diabetes you don't really have a choice. It's not a matter of having to make a healthy choice. It's a matter of that's the way it is. There's no way around it. It's more like the choice is made for you" (Audrey). Compliance with their diabetic regime was the only feasible choice available to them. *"You don't have a choice. You have to do this"* (Francine).

Regaining control of their diabetes was closely associated with the women's decision to follow their prescribed diabetic regime. Rather than remaining passive bystanders in diabetic care the women acted as active participants with the health care team in self-care and decision-making activities. Some felt they could understand their body in ways that differed from health care professionals and resented not having their needs met. They moved away from playing the victim of diabetes towards becoming active agents in controlling it. *"You have an active role and you can take charge of what's going on. Rather than just roll along"* (Helen). Strict adherence to their diabetic care routine led to an increased sense of self-efficacy. Frequent monitoring of blood sugars revealed needed information about their body's reactions to their everyday activities and changed eating habits. The women remained astute how their actions or in-actions influenced their blood sugar levels and their fetus's well-being. *"When I was first diagnosed I was really strict about my diet which is good because it gave me a sense of control. I found the monitoring really helpful because I just feel more in control when I know what's going on. Like you are in charge. That if I do X,X, and X that things will work out"* (Helen).

The women acquired new skills to help manage the diabetes, many of which are considered invasive. They learned how to check their blood glucose levels by poking their fingers and for some women, how to self-inject insulin. As the women became over time more knowledgeable about and familiar with their bodily responses to diabetic self-care measures their self-competency in managing their diabetes was enhanced. I recall Barbara's account of attending social gatherings during her pregnancy and how her adaptive behaviors had changed over time. *"At first you don't want to go anywhere because you didn't want to have to deal with this but when you get more comfortable with it it's a lot easier to deal with other things. Going out with people, going out with friends and stuff like that."* As their pregnancy progressed

overtime and the women obtained information about their pregnancy status, their comfort level to effectively cope with diabetes self-care improved. The etymology definition for comfort is from the Late Latin term 'confortare', meaning to strengthen greatly. Comfort, as a source of strength, was a powerful aid to the women's ability to manage and self-manage their diabetes. The women expressed feeling more comfortable with diabetes as they merged diabetes self-care in accordance to their specific individual needs. Acquiring more knowledge and skills about managing their diabetes resulted in a higher degree of self-competence. They learned the parameters in which they could live in managing the diabetes. *"I had a better understanding that I could cope with it and try to do my diet and stuff and keep the routine. Then I'm OK"* (Jane).

Through a redefining of self as someone with diabetes, the women overcame the initial negativity ascribed to their situation and themselves. As Lynne states, *"When you become diabetic it's almost like you have to become socialized into it."* Being comfortable with their situation the women could contend with their diabetes and not keep it hidden from others. It had taken on a different perspective. *"It's a big deal but it's not a big deal to be embarrassed. To not do it* (self-inject insulin, blood test) *because you are scared that people are going to talk. It's just part of life"* (Barbara).

To effectively assume diabetic self-care with a new discovered inner strength was a function of how long the women had experienced gestational diabetes. The experience of living and dealing with diabetes resulted in a development of embodied knowledge. The women had become attuned to their bodies and knowledgeable of what factors adversely affect their blood sugar levels. *"Like never before would I have thought that it would hurt my baby to have an extra glass of milk. Or have one or two more extra pieces of potato. I could eat the same exact things day after day and I would think that my blood sugars are still dropping down and that's when you realize it's not just your diet that you need to control"* (Gretchen). The control that they exercised was based on the knowledge gained about themselves through both internal (physical signs and symptoms, emotions) and external means (monitoring, health professionals). Proficiency at insulin injections, checking and interpreting

their blood glucose levels influenced their sense of success at diabetic self-management. There was a sense of being comfortable with having diabetes, as its management became part of the women's daily routine. *"I found that in the beginning it was hard but once you get used to it it's not hard anymore. It's really like routine"* (Francine).

The newly acquired personal knowledge gained through living with diabetes differed from the professional knowledge held by health providers. Both knowledge domains are significant to the women but the relevance of each changed over time. The point of diagnosis until they felt comfortable with the management of their diabetes was dependent upon the length of time (lived time) they were pregnant. The scientific knowledge acquired at the beginning of the women's experience with diabetes was critical to her ability to cope with the needed changes. As the pregnancy progressed the women learned more about their body, how their body was responding to the regime and how they felt physically and emotionally. This embodied knowledge facilitated some flexibility being built into their daily routines. In comparison when gestational diabetes was initially diagnosed the women became less structured and adjusted the prescribed diabetic regime to fit their usual daily routine.

Many women found aspects of their diabetic regime unrealistic and needed modifications to fit their day-to-day routine. Their confidence in diabetic self-care was a function of how long they had experienced gestational diabetes. As a result of an ongoing learning process the women developed expertise in diabetic self-care and a heightened awareness of their bodies and what would work best for them. They no longer needed to conduct their lives in a rigid manner. They felt competent in making necessary alterations to their diabetic regime without worrying about adverse consequences to themselves and the baby. *"It's really hard to fill their little books, write out everything. You are supposed to take your blood sugar 4 times a day. There are times when I didn't check it 4 times a day. Well there were times when my schedule didn't fit especially when because I worked shiftwork. I wasn't really concerned because I knew that the insulin I was on was controlling it well. I knew I was watching what I ate and I knew it was working"* (Audrey). *" When they started me on my diabetic diet I think it was at 7 or at 7:30 in the morning. I couldn't do it. I*

was working like from five in the afternoon until one in the morning. I wouldn't get home until 3 to 3:30 and I'm not getting up 4 hours later to have breakfast just to follow their plan. I said, 'I'll sleep in and I'll skip it and I'll just start my meals later" (Cathi).

As the women became more familiar with diabetes and became skilled in managing their diet, activity and insulin they began weighing the benefit of their behaviors against the potential risks they presented for self and their fetus. An element of rebellious behavior against the enforced restraints and control by others was a means to provide a sense of freedom and normalcy. Women who perceived that the diabetic regime had the potential to cause more harm than good took back control from health professionals. One woman told me of switching doctors when she felt her needs were unheeded. Another stopped attending the diabetic clinic and depended on her mother's advice and her own intuition for the remainder of her pregnancy. In an effort to normalize their situation the women occasionally altered their diet, succumbed to their cravings for something sweet and neglected to conduct and record a blood glucose test. Some women used the word "*cheating*" to describe occasions when they felt like falsifying blood sugar levels to prevent being controlled or chastised by their doctor.

The women faced uncertainties regarding the future health and well being for both themselves and their fetus. *"You worry about what's going to happen. How you have to deal with this and anything else"* (Barbara). Acquiring information through frequent glucose monitoring, ultrasounds and clinic visits helped to reduce the uncertainties associated with gestational diabetes. The temporal aspect of gestational diabetes facilitated the women's coping and endurance. They clung to the hope that once their baby was born that the gestational diabetes would be gone. The women demonstrated a present-oriented state of being and described living one day at a time assuming cautionary measures when carrying out normal day-to-day tasks. They were, *"doing the best that they can."* Continual monitoring of their blood sugar and baby's development was judged as both valuable and reassuring. *"It's was controlled and it's been watched. It's been monitored. It's really been taken care of. So I am not*

as concerned because I think it probably has a better chance of being a normal pregnancy" (Barbara).

The environment mediated the transition for these women in a dichotomous manner by being supportive and a source of stress. The women developed a dependency on blood glucose monitoring to assess their success in maintaining good diabetic control. *"It's good that I check it every day. If the blood sugar that I found is low I am very happy"* (Irene). Objective measures, such as blood testing served as a self-evaluation to determine how well they were controlling their blood glucose levels. *"Doing good,"* meant that they were able to keep their blood sugar levels within the recommended range. Ultrasounds were a welcomed means to gauge the size of the fetus. Concern about harming their fetus or requiring more intensive treatment, such as insulin, was associated with blood glucose results found outside the recommended perimeters. Extreme blood glucose values elicited self-blame and questioning.

Being diagnosed with diabetes presented as a major challenge to be faced and overcome for a successful continuation of their pregnancy to term. In one moment everything about their pregnancy experience, as they had known it, changed. The knowledge that they had gestational diabetes transformed every aspect of the women's understanding about themselves and their world. There was a loss of the taken-for-granted aspects of their life world. The life they knew and lived had changed and what lay ahead was vague and unknown. As the time to give birth to their child grew closer, the women acquired a mastery of skills needed to effectively balance their life. The women encountered a process that moved them from feeling controlled by gestational diabetes to being in control of its impact. However coupled with the feeling of being in control was a concern about their unborn child's well-being. The women felt a moral obligation to keep their baby safe from harm, which is illustrated, in the next theme, "being the responsible mother".

THEME III Being the responsible mother

"No matter what you have to do the baby's the focus" (Lynne)

Throughout the childbearing experience a pregnant woman does not journey in total isolation but travels along with her fetus. There is a unique relationship of 'oneness'. The body of the fetus exists within the body of its mother not as a separate distinct entity but as part of a connection with its mother that is deeply intertwined. *"When I think of the pregnancy it's us"* (Barbara). What happens to one inevitably affects the other. The theme "being the responsible mother " refers to the intense moral obligation and commitment that the women expressed towards the health and well-being of their fetus throughout their pregnancy and early postpartum experience. Responsibility is defined as a moral, legal or mental accountability and an obligation for which one is responsible (Merriam-Webster Dictionary, 1997). In her comment above Lynne speaks to the overwhelming responsibility she has towards her fetus as she proceeds through pregnancy.

The women described diabetes in pregnancy as being a risk to their baby's health as well as to their own. The women's attention shifted towards their unborn child and how it might be affected in utero or after birth by the gestational diabetes. Uncertainty enshrouded the health and well-being of the baby and throughout their pregnancy remained a source of constant worry that something could happen to their unborn child. *"I'm scared of the affects it's having on my baby. And all these fears now. What's gonna happen to my baby?"* (Francine). *" It's just the baby sometimes. Occasionally I'll wonder about her getting birth defects and stuff like that. This could go wrong or that could go wrong or what about this and what about that but as for myself it doesn't. I don't think about that."* (Kathryn) *"I know what diabetes has done to my mother. But I don't know how it will affect my child growing inside me"* (Gretchen). The women discussed their potential of having a large baby, a baby with birth defects, a difficult and painful childbirth, a cesarean section, and/or induction prior to term. Giving birth to a large baby was a terrifying prospect for many of the women. *"I'm scared of the baby being too big. Especially since my insulin is higher this time. That part really scares me. Like terrifying"* (Audrey). Others worried about the possibility of losing their baby from a spontaneous abortion. Concerns emerged about the potential for their child developing diabetes later in life.

The developmental mothering task of seeking and ensuring a safe passage for self and their fetus was emphasized throughout the women's childbearing experience. By acknowledging the risks associated with diabetes for self and baby the women became solicitous in conducting their daily activities. They demonstrated a sense of urgency to act on behalf of their fetus by using excessive caution. Being careful means displaying close attention to details of one's actions. It implies attentiveness and cautiousness to avoid making mistakes. *"I tried not overdoing something, like not overeating. Sometimes on the physical part I don't want to carry heavy stuff. So I have to be careful. This is the first one. Scared of losing the baby"* (Irene). *"That's the most important thing you're thinking about is your baby's health. You just want to take as good care of yourself as you can. It's not enough that you are trying to be careful at work and you are trying to be careful that nothing happens. Like being careful in a sense where I just don't want to damage myself or the baby. I don't want to lose the baby. And that's a big worry for me. Being careful all the time to not get so stressed"* (Diane).

Emphasis was placed on safeguarding their baby's health over their own health by remaining baby-focused. The women spoke of the moral obligation that a pregnant woman has towards her fetus's wellbeing. She is accountable for keeping it safe and unharmed. The women became resigned to the required dietary changes, lifestyle adjustments, frequent monitoring that were associated with their diabetic regime in order to give their best to the unborn child. There was a heightened moral responsibility for the sacrifice of one's self-determination for the sake of the baby. The women spoke of being altruistic where meeting the needs of their fetus took precedence over their own. *"It's not just yourself. If you are diabetic yourself, to think about what the risk is to yourself, the signs, the symptoms. But I might be feeling fine and it is affecting the baby. It's not just yourself you're thinking about. You have one that is totally dependent on you to keep it safe"* (Audrey).

Ensuring a safe passage dominated the women's pregnancy and early postpartum experience. The women were concerned about how their everyday activities might adversely affect their fetus. *"Like everything I do it's like, Oh, is this gonna be OK for my baby? Like this, this, this?"* (Jane). Closely associated with the

women trying to do what is right were feelings of self-blame and culpability. Francine while pregnant wondered, *"What harm am I doing at this time, this short time."* Are they to blame? *"It concerns myself and it concerns both my kids that passing on my genes to my kids and having them have problems down the road with it. I'm still concerned with that"* (Barbara).

Undergoing blood glucose screening during their pregnancy did not require much deliberation and most of the women considered it a routine part of their prenatal care. Pre-screening for gestational diabetes was perceived as a strategy to ensure a positive maternal and neonatal outcome. Some women spoke of the screening test as part of a moral responsibility to ensure the well being of the anticipated unborn child. To neglect a prenatal test that can facilitate a woman to produce a healthy baby was viewed as immoral and unacceptable behavior. To not want to know the health status of the fetus and pregnancy was an act of selfishness. *"It's important to know because of how important it is. I mean you can't be selfish and just not want to know. You have to know for the baby"* (Diane).

Helen's astonishment that some people take a "laissez-fare" approach to screening for diabetes in pregnancy addressed the moral component to becoming a mother. She states, *"There was an article I read last week in one of the magazines. I should have gave it to someone because the theme was 'Great Expectations' and the whole thing was about that diabetes isn't that serious and gestational diabetes wasn't serious. I was just shocked to read that. That there's no long-term consequences. I thought it was really horrible. They have it sitting right there. I read this at the diabetic clinic and I was totally appalled by it. They were saying that they didn't advocate very much like to do very much about it. They were just saying, like to not do much about it. They were just saying it will go away and you will have a big baby. You have this little baby inside you and you don't have to take care of it?"* To what extent does reproductive technology and prenatal screening tests play a role in assuring a safe childbearing experience?

Although the prescribed diabetic regime was described as strenuous and restrictive the women possessed the moral obligation to ensure a positive outcome for both self and the fetus. Their focus on the fetus was associated with unrelenting

selflessness and emphasis on compliance. *"I'll do anything. I'll bounce on my head for this baby. If they tell me I have to shove needles into my eyes, I'll do it for this baby"* (Lynne). The giving of self was intensified, as the women perceived it was their duty to endure whatever sacrifices needed to follow the prescribed diabetic regime. *"This is a serious thing. Diabetes is fine for you. We can all take care of our own lives and choose what we want to do for your own body. But when we choose to bring another life into, it changes things. It's not just you that you are worried about"* (Lynne). The women had no other option but to accept that they had diabetes and to follow their recommended regime to the best of their ability. As Kathryn explained, *"It's just something I've got to do and like there is no sense in complaining about it all the time. It's just something that if I want a healthy baby I have to do this. It's the bottom line."*

Keeping their blood glucose levels controlled and within the recommended range was deemed critical for the health of the fetus. *"It's really risky for the baby. I would tell anybody to do what they tell you to do to keep your blood sugars as stable as possible. For the sake of the baby"* (Audrey). Extreme high or low blood glucose levels were an additional source of stress for the women. A common question was what harm were these levels doing to their fetus? If their blood glucose levels became elevated the women worried about the need to commence insulin administration. When blood glucose levels were found at extremely high levels the women's fear about having a large sized baby escalated. Their worry was an impetus to remain vigilant in diabetes management. Maintaining blood glucose readings within the recommended range was an indicator that she was doing well.

Internal and external factors dictated that the women do what is right for the sake of their anticipated unborn child. These pressures were manifested as controlling actions particularly by the spouse, other family members and friends. Every action by the women was under strict surveillance in an effort to prevent any harm to the fetus.

The women developed a dependency on the frequent monitoring scheduled throughout the pregnancy. They underwent many ultrasounds to determine the well-being of their fetus. Clinic visits for follow-up care to monitor the fetus, the diabetes

and their pregnancy helped to ease the women's uncertainties and concerns they felt. Frequent blood glucose monitoring provided the women with feedback they needed on how successful they were in controlling their diabetes. The women welcomed ultrasounds to obtain feedback about their fetus's growth and development. *"It was good to have all those tests done to make sure everything was OK "* (Ellen). *They did an extra ultrasound at 32 weeks. That was kind of re-assuring to do that. Just to see that the baby's developing normally and it's not too big"* (Helen).

Feeling fetal movements provided a source of relief and was indicative of the baby's health. The women found fetal kicks as comforting and indicative that all is progressing well. *"As long as it keeps kicking me everyday and every kick makes me feel comfortable to know that"* (Barbara). Absence of any fetal movements was a cause for concern. *"At night time I will feel my stomach and there is no movement. I'm scared. Well what's going on. And then it's like rush of the week when the baby does move. But for two days I felt like it wasn't moving but maybe it was in my mind. I was just wondering if I should see the doctor. Can you just check and hear. I am just trying to be calm. Like when my blood sugar shows high and I get all worried and then the baby will move and it's like a reminder that this is mine inside and that's what I have to look forward to"* (Francine).

After their baby's birth the women received validation that the actions they took throughout the pregnancy were beneficial for their own and their baby's well-being. It was critical for the women to know the baby's size and health status. *"It was all worth it. He was just beautiful and I thought the first week, that's what I kept thinking, 'He's not this fat little baby.' It was so important and when I saw that it was just validated everything that I did. He was on the 96th percentile for weight and 95th percentile for height. He was almost like he was thin actually. So it made me feel like I did a good job"* (Helen). To these women giving birth to a small sized baby at was an important indicator of their success at diabetes management.

Worry for the well being of their baby continued into the postpartum period. What are possible long-term effects? Would their child develop diabetes? When her preschooler seemed to be drinking more than usual one woman tested her child's blood sugar worried that she might be diabetic. Their thoughts about the effects

gestational diabetes on the future heath of their baby were related to how long they had experienced gestational diabetes and how well they felt it was controlled. *"I still wonder if the baby's going to be OK. I keep hoping that it will be OK because the sugars been controlled at an earlier stage. Maybe it has a better chance of being healthier down the road. It may not have the same problems that the first one might have. The first one was caught at a later date so she may have some problems with her sugars down the road. I am more concerned about that one as opposed to this one because it was caught so early"* (Barbara).

As the women progressed through their pregnancy their fetus remained predominantly on their minds. There was an exaggerated commitment to fulfilling their moral obligation to being responsible mothers. They looked forward to the birth and remained hopeful that everything would be fine. Although present but not explicitly evident in these women's stories were thoughts about the consequences that gestational diabetes might have on their own health and well being both short and long term. *"What happens if doesn't go away. I was really scared. Shorter life span, heart problems. Everything goes through your mind. Am I going to be around to watch this kid get married?"* (Barbara). The final theme, "being transformed" refers to a developmental process that was associated with the women's experience of a pregnancy encumbered with gestational diabetes. Gestational diabetes forced an abrupt change in the women's lives. Living with diabetes had altered the women's view of the present and future health and well-being of themselves and their family.

THEME IV Being Transformed

"I guess having gestational diabetes has really changed my whole life!" (Barbara)

The birth of their baby ended one phase of the women's childbearing process and marked the beginning of another, the early postpartum time and life as a new mother. At their baby's birth the women had reached a summit and could now reap the rewards of the hard work they had undertaken to get there. By eight weeks postpartum the women had discovered that the gestational diabetes had been resolved

and no ill effects had been bestowed upon the infants. However, the women did not reach this point of their pregnancy experience unchanged. The final theme, "being transformed" refers to the women's description of their pregnancy experience as transforming in how they viewed their health and influential in terms of how they planned to conduct their lives and that of their family in the future.

"Know also that wisdom is sweet to your soul; if you find it, there is future hope for you and your hope will not be cut off " (Proverbs 24:14). The statement taken from the Book of Proverbs refers to the accumulated scientific and experiential knowledge that the women had acquired while pregnant with gestational diabetes. Their embodied knowledge served to enhance the women's motivation and self-efficacy to make changes and in turn be changed. Despite the mental fatigue and frustrations associated with adhering to their diabetic regime the women had been learning to cope and in the process had been transformed. In speaking of her dietary changes Barbara found, *"My diet. I know it so well now that I will end up sticking to it afterwards because you are just into that groove. It's so much part of your lifestyle."*

The women's sense of lived space or spatiality felt throughout their pregnancy experience was ever present in their stories. The world in which they had found themselves while pregnant was constraining and oppressive. Receiving the news that their diabetes had resolved in the early postpartum period was meet with elation. The intense controls and restraints had been lifted. The women spoke of being happy, relieved and free finally free from the burdens affiliated with diabetic care. *"Nobody can control me anymore. I can eat anything I want."* (Irene) *"I was happy! No more monitoring all the time. It was a relief learning that it was gone"* (Cathi). *"You're free!"* (Gretchen). Was this a sense of being released from chains?

The euphoria associated with knowing that their diabetes had disappeared was tampered with the realization that their lives have been forever changed. Their risk of encountering gestational diabetes in subsequent pregnancies or developing Type II diabetes later in life weighed heavily on the women's minds. *"I think the biggest issue is that I will be diabetic all the time. I just think that I've been on insulin a lot longer this time. I just feel a bit more of a concern about it happening, with being*

permanently diabetic" (Audrey). *"I'm concerned that it'll come back but I won't be pregnant the next time. Like I'll have Type II later on. I guess you could say I'm concerned whether it will be happening 6 months down the road or two years down the road or ten years down the road. That's a concern that will always be there. Will it come back?"* (Barbara).

The women's overpowering concern of diabetes 'coming back' acted as a catalyst for them to make and maintain health related lifestyle changes. *"I was really happy that I wasn't diabetic anymore. But in a way I have to get on it. Stick with it. Stick with the diet and everything. I don't want to have diabetes. It's hard"* (Jane). Diabetes led to overall transformation in the women's lives. The women utilized the personal and scientific knowledge they gained about diabetes, diabetes management, self and body to take control of their life circumstances and to make choices that would enhance their long term health and well-being. *"I know I have to be careful because I'm high risk to get it down the road. But you can't really know. You just do your best. Just be vigilant."* (Helen) *"The diabetes did upset me a bit because it does increase your risks for later in your life. So it does put me on track for losing weight, to keep my weight down and keep in shape"* (Gretchen).

The women's motivation to permanently entrench the lifestyle changes involved in their diabetes self-management was in contrast to their health behaviors prior to being pregnant. Many women stated that previously they didn't care that much about their health, dietary habits and activities. *"Cause before I didn't even watch what I eat. I know like I have to read the labels and stuff and see what's the ingredient. So I am more aware now than before. Like before I didn't care"* (Jane). Having diabetes affected their attitudes about their own health. Some reflected on their own morbidity and mortality. *"I see myself as down the road being at risk. Which makes me realize that if I want to be around to watch my kids grow up I have to do more than all this stuff. I do what I have to, to get healthy. I know that I have to I know that I have to do it now because it is something that I have. It's like heart disease or something"* (Barbara). *"I'm gonna continue what I'm doing down the road. I don't want to be sick down the road. Like when I have my kids I can't go with*

them and so I want to be energetic so I could be with them. That's where I want to be. So I'll try" (Jane).

In spite of the negativity associated with gestational diabetes the women pointed to positive ramifications. The women described feeling healthier, more energetic and desired to maintain this level of well-being. The diet enforced throughout the pregnancy had become a habitual part of the women's eating patterns. *"Everything's changed. I go for more healthy diet. And I feel good than before"* (Irene). Many of the women concluded that if they hadn't encountered gestational diabetes the shift towards a healthier lifestyle might not have occurred. Diabetes had got them to what one woman called a *"good place"*.

These women viewed having encountered diabetes as a revelation and for some a serious warning that changes in their lifestyle were necessary. *"It's saved my life or something. So like for me it was a good thing"* (Jane). Gestational diabetes was described with terms such as, *"an eye-opener"*, *"eye opening"*, and *"a wake-up call"*. The women reflected on past their health behaviors and utilized their knowledge and skills to implement healthier choices for themselves and their families. *"I do what I have to do to get healthy. I know that I have now because it is something that I have and it's just like heart disease or whatever. I'm a little more comfortable with knowing that I really have to do something because it is not just me controlling it"* (Barbara).

They were determined to take preventive actions to avoid any re-occurrence. They were committed to make any necessary changes in their lifestyle behaviors to help ensure a diabetic free future. *"I was able to control my emotions a little bit better and give myself some incentive that I'm not going to let it take me. I'm not going to get diabetes when I'm older. I'm not. I don't want to have to take insulin. I don't want to have to watch what I eat everyday"* (Gretchen). The women's experience of living a controlled pregnancy served as a reminder of what their future may entail later in life. Lynne talked about wanting to avoid insulin. She stated, *"I'm hoping to get through this and then when I start my next phase of trying to get rid of all this. To get rid of all this insulin. I will find a different more capable way. I*

want to be able to exercise. I do not want to eat for my insulin. I can't live like this. I can't eat for my insulin".

An educational aspect of gestational diabetes was revealed in the women's increased awareness of their body and bodily reactions, healthy food choices and useful exercise regime. *"Diabetes taught me my body"* (Lynne). They knew what foods were problematic in terms of controlling their blood sugars levels. They made lifestyle changes that they probably would not have made. The women felt they had acquired the necessary knowledge and skills to continue with the lifestyle they had grown accustomed to during their pregnancy. The women expressed a desire to achieve and maintain a higher level of wellness as compared to their pre-pregnant status. *"If anything it showed me how to eat better, to eat healthier. Like I don't abuse food"* (Diane). They were hopeful that if they could take action and be in control of their destiny and prolong the inevitable. *"My body is going to come up with it sooner or later down the road. How much sooner or how much later depends on what I do"* (Barbara).

As the women talked about their pregnancy experience, thoughts of self-blame and "if only" emerged. Were they totally responsible for developing gestational diabetes? Is there anything they can do about prevention? As Barbara lamented, *"I should have gotten away from TV more and then done few more things. Had I gotten out and didn't eat so much before I got pregnant then it would have been easier. I think maybe if I knew then what I know now it would be a bit different. I think that my lifestyle contributed to the weight, contributed to the diabetes and stuff like that."*

By the end of their pregnancy journey the women felt increased self-confidence in diabetes self-care. They were able to reconfigure their situation in a positive way and were more relaxed and comfortable with their pregnancy and diabetic state. A sense of being empowered evolved as the women became knowledgeable and skilled about their diabetic management, trusted their embodied knowledge, and recognized that they had choices and could take back control of their lives. The women's level of self-efficiency increased as they realized that they could do this. *"Basically it's felt good to know that I could do this. I feel empowered and*

stuff like after this. Like in the past few years I haven't looked after my body as well as I should. I've always struggled with my weight. So I feel like after the baby's born I will get straightened out. So it's been positive" (Helen).

A definition for the verb to empower is to enable or promote the self-actualization of someone (Merriam-Webster Dictionary, 1997). Empowerment refers to the action of empowering or the state of being empowered. To understand the term empowerment the concept of power needs defining. Power is derived from the Latin word power that means to be able and to have the ability to choose. Empowerment is synonymous with such terms as, allow, sanction, authorize, give power to, make possible, commission, invest with power, and facilitate. To be empowered in the context of these women's experience speaks of their felt inner power and strength to cope with a diabetic pregnancy.

The women became knowing subjects of their bodies and it's reaction to their pregnant body with gestational diabetes. They gained knowledge about diabetes and what was involved in its management. This local knowledge of their lived experience was utilized to take control of their circumstances and to make choices that would enhance their long term health and well being. These women are the means and generators of the power that they exercised particularly in the postpartum period.

The definition of empowerment is also closely related to the term comfort. To be comfortable refers to an inner strength of being. The women expressed a feeling of comfort with their diabetes and its management as their pregnancy progressed towards term.

The women's increased knowledge about the effects of diabetes on their overall health and wellbeing formed a basis for the making long-term decisions. They may not have made the dietary and other lifestyle changes if she hadn't encountered diabetes. *"I think that it probably wouldn't have happened. I know that eating properly wouldn't have happened because I probably wouldn't have made the food life changes for sure"* (Barbara).

The women looked forward to the future health and wellbeing of themselves and their child as they implemented lifestyle changes. The women worried about the future health of their children and tried to make choices in terms of enhancing their

well-being. *"It concerns both my kids and having them having problems down the road with it. I'm still concerned that they get juvenile diabetes. So I'm trying to take measures to making sure that my kids learn that TV is fine we can watch it but there are other things besides sitting in front of a TV. I want to try and give my kids that teaching because I may not have cared that much. But it happened to me now I am a little more concerned. It isn't passed on to them and they are aware, as they get older. I'll help them to choose the right foods, so when they get older they can choose the right foods and like help them to like their vegetables and that kind of thing. So that way down the road when they get older they'll just know what to choose and they're not always gonna be choosing that hamburger or the french fries and that kind of thing"* (Barbara).

Like a mountain hike the pregnancy experience for these women proceeded sequentially and was characterized by plateaus, peaks and retreats. After the initial shock upon discovering gestational diabetes the women progressed to a level of acceptance of what had happened. They dealt with the issues regarding loss of control by focusing on their moral commitment to their expected child and keep it from harm. Although there was a period of no escape from their diabetes the women recognized its temporary status and remained hopeful it would eventually go away. The women struggled to achieve a state of equilibrium and normalcy during their pregnancy as the diabetes was integrated into their lives. They had been changed by their experience and in the process had gained self-knowledge about their own inner strength to cope. The last two chapters are a discussion of what knowledge we can gain from these women's storied experiences, how this knowledge can be used in practice and what further research is warranted.

CHAPTER SEVEN

What can we learn?

It is not easy to be in the medical profession. One is constantly having to balance the high expectations of modern health care with the need to respect the human soul (Mauger, 2000, p. 4).

In this phenomenological study women's lived experiences of a pregnancy complicated with gestational diabetes were explored. The findings of this study provide nurses and other health professionals with insights about the complex nature of gestational diabetes as well as the opportunity for continual dialogue. Living a controlled pregnancy, balancing, being a responsible mother, and being transformed were four themes that emanated from the collective voices of the women who shared their stories about their pregnancy experiences with me.

Facing the unexpected

Pregnancy is associated with specific expectations, such as; the woman's body adapts to accommodate the growing fetus, lasts nine months, and ends with a healthy baby and mother. However, as revealed in this study pregnancy did not unfold exactly in the way that the women had expected or hoped. To develop diabetes while pregnant caught many of the women off guard. Gestational diabetes was not anticipated by many of the women and the diagnosis initially left them shocked, scared and anxious. How something so serious could really be happening to them when they felt fine was a common thought.

For most of the women gestational diabetes mellitus had emerged inconspicuously and presented a complex process during which their perception of self and pregnant body was restructured. For other women who had previously experienced symptoms the reoccurrence of gestational diabetes increased their anxiety. In a simple moment their expectation or hope for a normal pregnancy was shattered and the women were suddenly facing new challenges and unknowns. In addition to confronting the normal adaptations and discomforts of being pregnant to have gestational diabetes meant the women faced the demands of living an "at risk" pregnancy. The concept "risk" was an integral part of the diabetic pregnancy

experience and changed the women's perception of their pregnancy as one progressing normally to one that was now in peril. Any health risk the women perceived to be a possibility for themselves, their baby or their pregnancy was given great significance. A previous experience of gestational diabetes, a history of being overweight, poor eating habits and a sedentary lifestyle were factors that if present, weighted heavy on the women's minds in terms of suggesting their culpability and contribution to their health risks.

Similar to women with gestational diabetes, childbearing women with pre-existing diabetes (Type I or Type II) have an increased risk for maternal and neonatal mortality and morbidity with pregnancy (Avery & Rossi, 1994; Buchanan & Kjos, 1999). The attainment and maintenance of normal blood glucose levels throughout pregnancy is required by each group of women. The sudden onset of gestational diabetes is associated with the woman having to learn about diabetes, acquire new skills and implement a diabetic regime. The woman who is diabetic prior to becoming pregnant already has the knowledge and management of diabetes as part of her lived experience. In contrast to pre-existing diabetes that is permanent gestational diabetes is temporary in nature. Blood glucose tolerance for women with gestational diabetes returns to normal after delivery. Encountering gestational diabetes acted as a warning signal to the women that they needed to change their lifestyle and hopefully prevent developing diabetes in the future.

After receiving a positive glucose tolerance test result, the central message the women heard from external sources was "your blood glucose is outside the normal range. If left unmanaged dire consequences could result for you and your baby. You have gestational diabetes and it needs to be managed and brought under control." The value of diabetic screening may be associated with its ability to identify GDM leading to appropriate interventions. A sense of urgency surfaced that demanded the women to immediately incorporate major lifestyle changes into their daily lives. The women were referred directly to a diabetic outpatient clinic for further follow-up medical care and diabetic management by a diabetic health care team. External control of the women and their pregnancy by family, friends and health care

professionals became further ensconced to avert any adverse outcomes for the mother and her unborn child.

Issues of control

The concept "control" was intrinsic in some form in all four identified themes and reflected the challenges the women faced and struggled to overcome while living with gestational diabetes. Control emerged as a major thread that intertwined the women's stories and validated the findings of previous research pertaining to individuals living with diabetes (Berg & Honkasalo, 2000; Doherty-Sullivan, & Hunt-Joseph, 1998; Gillibrand & Flynn, 2001; Hartnick, 1998; MacLean & Goldman, 2000; Paterson & Thorne, 2000; Paterson, Thorne, & Dewis, 1998). The word "control", a derivative of the Latin terms contra- and rolulus, means to check, test, or verify by evidence or experiments; to incorporate suitable controls in; to exercise restraining or directing influence over; to have power over and; to reduce the incidence or severity of especially to innocuous levels (Merriam-Webster Dictionary, 1997). This definition depicts the external control measures often placed on any woman's pregnancy as well as the extra surveillance and medical intervention deemed necessary to ensure positive maternal and neonatal outcomes when a pregnancy is considered at risk.

In western society control plays a major part in the medicalization of pregnancy and childbirth care. Medicalization of pregnancy refers to the emphasis placed on the medical model and the endorsement of health professionals as experts of pregnancy, the pregnant body and the childbearing process. For example, the notion that physicians are the legitimate authorities concerning the care of pregnant women sanctions their power over pregnant women's bodies and infringes on women's personal autonomy regarding the childbearing process. Health professionals often consider a pregnant woman's compliance to treatment plans as a positive attribute and indicative that she is taking responsibility for her unborn child's safety. Under this paradigm pregnant women are expected to comply with any recommended medical interventions emphasizing their dependency role in the health provider-client relationship. Addressing her own interests and needs during

pregnancy the woman may be interpreted by others as being non-compliant, selfish and putting her self and fetus in danger.

Pregnancy today exists primarily within the public sphere where control of the pregnant body has shifted away from a pregnant woman's private domain. The physical, psychological, social and spiritual changes associated with pregnancy contribute to a certain loss of control for most pregnant women (Mercer, 1995). Associated with pregnancy and childbearing is the conceptualization of both individuals and collective agents (the woman, family members, health professionals, lay public, government, and society) being responsible and capable of making key decisions that will influence the well being of the fetus and the mother. A moral discourse is posited and directed towards an external management of women's bodies and their lives throughout the childbearing process. Rothman (2000) challenges the medical monopoly on pregnancy management and suggests redefining childbirth as not merely being a medical event. She maintains that by viewing pregnancy as a natural event the medical dominance over the childbearing process decreases and control of a pregnancy experience would rest more with the mother.

The three key culturally based characteristics of pregnancy and childbearing identified by Balsamo (1999) have relevance to the control of women's pregnancy experiences portrayed in western society. First, Balsamo asserts that a pregnant woman is denied sole ownership of her body and consequently becomes a biological spectacle to be observed by others. Childbearing is characterized with the perception that the pregnant woman is less than capable of making choices that are in the best interest of herself and her anticipated unborn child. She is viewed as an "object" to be scrutinized and managed. Second, the potential child's rights to be born, nourished and protected ascend the rights of the mother. Finally, pregnancy is perceived as a satisfying condition for women and consequently a pregnant woman would endure "any discomfort, humiliation, or hardship to experience this blessed event" (p. 232). Acknowledgement of these three characteristics upholds a moral obligation, on part of society, towards the baby's safety and supports external control of the actions of pregnant women to ensure optimum maternal and neonatal outcomes. Many of the women described feeling an increased obligation to heed the advice of others, to

comply with recommended screening tests and interventions, and to act in the best interest of their anticipated unborn child.

Rothman (2000) suggests that in a patriarchal society ownership of one's body may not translate to a woman possessing any real sense of control of her pregnancy and pregnant body. Her actions during pregnancy are subjected to the judgment of others. The medical narrative implicitly and explicitly addresses pregnant women's competence as a self-agent in any moral decision making process (Talbot, Bibace, Bokhour & Bamberg, 2001). This argument is based on the viewpoint that the pregnant body is the property of someone else rather than solely owned by the woman (Rothman, 2000). The well-being of the fetus is paramount further jeopardizing women's autonomous decision making ability while pregnant. As noted by Oakley (1994) " the wombs of women whether pregnant or not are containers to be captured by the ideologies and practices of those who, to put it simply, do not believe that women are able to take care of themselves" (p. 292).

The concept control embedded within the diabetic pregnancy experience was revealed in three dimensions, namely, loss of control (body, self-determination), being controlled (externally, internally) and taking control (diabetic self-management). The feeling of loss of control and being controlled played a prominent part of these women's childbearing experience and set the stage for the subsequent actions they took to self-manage and take control of their diabetes. For example, when the women received a positive glucose tolerance test result, their pregnancy was considered "at risk" for adverse maternal and neonatal outcomes necessitating their lives becoming highly regimented, structured and under the intense continuous surveillance of others. Encountering diabetes significantly transformed aspects of their daily life, such as, their basic day-to-day activities, dietary habits, and usual regimes. The women spoke about the difficulties of changing their diet, preparing separate meals, adhering to a rigid regime, attending a multitude of appointments, and coping with the financial burden of diabetic supplies. Altering their diet and dietary habits were identified by the women as tiring and one of the most arduous components of the diabetic regime. Food and its consumption are strongly grounded in a person's cultural and social norms making modifications challenging. Similar

difficulties associated with adhering to a diabetic diet and strict regime have been reported in previous research with pregnant women (Lawson & Rajaram, 1994).

Pregnancy itself presents as an event where the relationship between self and the pregnant body becomes altered. Being pregnant and diabetic forced the women to look within and develop a new relationship with the body and self. In normal daily functioning a person lives in what Van Manen (1998) describes as a livable relation with the lived body. He suggests that a person's sense of being is based on their perceived capacity to achieve and maintain some degree of control of their body and their everyday lives. In a state of wellness a person is capable of conducting his/her usual tasks of daily living with a certain degree of autonomy. If this capacity to be an autonomous being is perceived as adequate, then exercising control as a behavior doesn't need self-conscious monitoring. In a state of well-being decisions regarding the person's everyday functions are carried out without much thought or questioning by self or others. Encountering diabetes during pregnancy increased the women's self-consciousness of their lived pregnant body although there were often no overt symptoms. The asymptomatic nature of diabetes left the women feeling a loss of bodily connectiveness that created their need to stay astute.

The women's descriptions of living with gestational diabetes were congruent with the findings of a phenomenological study conducted by Berg & Honkasalo (2000) to describe the pregnancy experiences of women who had previously been diagnosed with insulin-dependent diabetes mellitus. They noted that pregnant women with pre-existing diabetes described a loss of control, an awareness of having an un-well body, exaggerated responsibility, constant worry, self-blame and pressure. These researchers suggest that the objectification of the women's body is an integral part in women's lived experience of pregnancy and diabetes. Similar to the findings of Berg & Honkasalo's study, the women with gestational diabetes described experiencing their pregnant body as being separate from the self and an entity to be scrutinized, probed and measured by self and others. As the control of their pregnancy and the diabetes shifted to health care professionals the women felt increasing objectification and distance from others. A diabetic pregnant body emerged and confronted the pregnant women as something that stood before them,

further exemplifying the concept of body as object. The women described their body as being out of control. Their body as agent acted independently of the self as noted by its unpredictable and erratic blood sugar levels. Coupled with the external control measures imposed on them, the women described frustrations trying to stay in charge of what was happening internally to their pregnant body.

Experiencing a prolonged broken relation between one's self and one's body leads to a state of 'dis-ease' (Van Manen, 1998). Comparable to previous research on the experience of diabetes and pregnancy the women revealed a heightened vulnerability associated with their loss of bodily control, particularly in their attempts to manage their blood glucose levels (Berg & Honkasalo, 2000; Lawson, & Rajaram, 1994). Their struggle to cope with an unruly body involved the women's fixation on checking their blood sugar levels and undergoing various prenatal tests, both actions that further objectified their body.

In discussing their findings, Berg and Honkasalo (2000) described the diabetic women's pregnancy experience as "being controlled by blood glucose levels for the child's sake." (p. 41). Feeling a loss of bodily control and being controlled by blood sugar as described by the women with gestational diabetes paralleled the previous research findings. Pregnant women with either gestational or pre-existing diabetes faced having a body that responded erratically and became disassociated from the self. In the present study blood sugar levels were a significant factor influencing the women's day-to-day functioning. The actions of the women, such as, when they could eat and what they would eat, when they could exercise, what activities they could do, and what social events they could accept became dependent on their blood sugar levels. Self-monitoring of blood sugar, self-administering insulin, and keeping meticulous records of blood sugar levels, amount of insulin injected and type and amount of foods eaten emerged as key factors that influenced the women's everyday life activities.

Self-body relation and control

While gestational diabetes is a pregnancy-induced condition, it has been socially constructed as being a disease state. For some of the women being diabetic presented a negative stigma and signified that they were in some way sick and

unhealthy. Frank (1995) in his book *The Wounded Storyteller,* states that during an illness, people experience distinctive problems when they continue to be their familiar lived body. He asserts being a body involves the person's resolution of four general problems of embodiment, namely, control; body-relatedness; other-relatedness and desire. The self-body relation of a person's being addresses each embodiment problem by using strategies from a wide range of possibilities. These general problems of embodiment and their resolution were relevant in further understanding these women's stories of lost control and being controlled.

Within the problem of control, questions arise related to a person's ability to accurately predict the dynamics of their body functions as well as to regulate their body's functioning. The women in this study expressed difficulty with predicting their blood sugar levels with any certainty, which led to increased concern and anxiety about their baby's well being. Fears mounted about possible adverse effects of any abnormal blood sugar levels to the baby. They were challenged to stay attuned of their bodily responses to any diabetic self-care measures taken but were often unsure of what to eat or do to successfully manage their diabetes. "*Doing good*" signified the women's successful achievement in maintaining their blood sugar levels within the required range. Dealing with their diabetes affected body-relatedness as the women's bodies were further objectified and blood sugar became their primary focus. The problem of body-self relationship was a function of the women no longer being in unison with their body. The bodily responses were foreign, unpredictable and seemingly uncontrollable resulting in much discomfort and un-ease. When their diabetes was judged by objective measures as being controlled (i.e., they were euglycemic) the women felt more associated or 'in sync' with their body.

The effect that gestational diabetes had on other-relatedness was depicted in the women's interactions with others in both formal and informal contexts. Health professionals, family members and friends begin to challenge the women's autonomy and decision-making abilities thus affecting their sense of being in control. Throughout their pregnancy the women were acutely aware of the controlling nature and constant surveillance by others on their behaviors. They talked about their

frustrations of others controlling their everyday activities and undermining their independence as they tried to cope with diabetes self-care.

In their interactions with health care providers and family members the women made attempts to have their needs heard and understood. The women described spouses, family members, friends and health professionals who did not listen, understand or value the complexity involved in the experience of living with diabetes while pregnant. Their interactions with others both professional and familial were at times characterized as both frustrating and confrontational. The women's descriptions of their interactions with health professionals were similar to those of previous researchers on uncertain motherhood where tensions exist between the scientific facts and medical care and the personal knowledge that was acquired by a mother's actual experience (Field, Marck, & Bergum, 1994).

The negative stigma attached to having diabetes while pregnant played a dominant role in the women's initial adjustment to the diagnosis. Many felt embarrassed by the diagnosis and took action to minimize their initial embarrassment by keeping their condition hidden from others. Concealment of the diabetes from the external world was a means of protecting oneself from any adverse reactions of others. The women needed to first acknowledge their condition and to redefine themselves as a person with gestational diabetes before they could reach out to others. Sufficient time for the women to experience life with diabetes was crucial as it allowed them to become accustomed to their changed pregnant body, the diabetes and its management. Until they felt a sense of ease in their own body-relatedness, the women's relationships with others remained distant and strained. Gaining knowledge and skill in diabetes management helped to ease the impact of the disease on their sense of being.

Many women used the words "*becoming comfortable*" with having gestational diabetes. Feeling comfortable was intrinsic and by accepting the fact they had diabetes and could effectively engage in self-care their perception of others' negative reaction towards them diminished. Diabetes was no longer a big deal. Although the women acknowledged the physical ramifications of having diabetes, it was no longer seen as a personal flaw or something to be embarrassed about. However their

judgment of others' responses towards their diabetes had a dichotomous nature. Actions by family members and friends were considered caring gestures while simultaneously seen as controlling. Health professionals were valued for their expertise but were at times criticized for their condescending manner.

Frank (1995) states, "Illness can instigate new reflections on how to be a body producing desire" (p.39). As their pregnancies advanced the women became more knowledgeable and proficient at managing their diabetes. Through accumulating personal knowledge and expertise about diabetes management and combining it with acquired scientific knowledge they found a personal meaning in their pregnancy experience. Berg and Honkasalo (2000) suggest that the pregnant women living with diabetes focus on their body in a new way. Even the women who had pre-existing diabetes found their pregnancy experience a challenge to overcome. By acknowledging their diabetic status the women decided to deal with the diabetes and subsequently regain some control of their lives. Experiencing success in diabetic self-management increased their comfort level and sense of self-efficacy. The women remained hopeful and looked forward to life without diabetes after their baby was born. They were motivated to incorporate their newly acquired knowledge and skills so that they could lead healthier lifestyles and prevent the onset of Type II diabetes later in life.

In her description of three progressive levels of relation between the self and the body Gadow (1980) offers another model applicable to these women's bodily experience while pregnant and diabetic. At the first level of Gadow's model, "primary immediacy" there is an alleged unity of one's self-body existence in the world. At this stage we are aware of our body not as something separate from our being but "it is the conscious capacity to act, the experiencing of my action as one in myself "(p. 173). In addition to the perceived ability to affect one's world, the immediacy of lived body includes an awareness of one's vulnerability to being acted upon by the world. The primary immediacy of self-body relation could be considered reflected in the women's lives prior to conception and the diagnosis of gestational diabetes. Prior to conception the women would not encounter the natural changes of

the pregnant body and the additional modifications associated with gestational diabetes.

At the second level, "disrupted immediacy", Gadow suggests, " the body and self are experienced as acting upon one another, each affecting and affected by the other, each in turn determining the other" (p. 174). This second level of the self-body relation is pertinent to the first identified theme "living a controlled pregnancy." Gadow states the immediacy of the lived body that is present at the first level of self-body relation is shattered when a person experiences an inability to act as desired or to avoid being acted upon in ways that are undesirable. Living with gestational diabetes involved a loss of bodily control because of unpredictable blood sugar levels that were difficult to successfully manage. Being monitored and under the constant surveillance of health care professionals, family members and friends increased once the women were diagnosed with GDM. Their inability to control the diabetes and exercise their autonomy affected their self-perception, leading to a sense of powerlessness and dependency.

The third level of Gadow's self-body relation, "cultivated immediacy" helps to explain the actions the women undertook to regain control of their situation by balancing their lives. At this level there is a struggle in the self-body relation where the self must objectify the body and overcome the constraints present at the previous level of body-self relation. Duration of gestational diabetes was an influencing factor in the women's movement towards a renewed relationship with their pregnant diabetic body. As their pregnancy progressed the women's awareness of their bodily responses and knowledge about diabetes management increased, thus facilitating the integration of diabetes into their everyday lives. For the women, the self eventually acquired a sense of mastery that creates a transformed unity of the self-body relation or "cultivated immediacy" as described by Gadow (1980).

Self-management and control

Loss of control experienced during their pregnancy was a factor in the women's decision to acknowledge their diabetes, to comply with their diabetic regime for the sake of themselves and the fetus, to overcome the challenges of being diabetic, and eventually regain a balance in their lives. Although the women described living a

very regimented life, it was carrying out the minute tasks of diabetic management that provided a means for them to regain a sense of control. They lived in the present, that is, a day to day existence or as one women stated, "*taking one day at a time*." In an attempt to regain a sense of control the women actively sought information about diabetes management and judged its utility and relevance to their particular situation. The women spoke of taking control, i.e., controlling how they could deal with their diabetes.

Choosing to follow their prescribed regime facilitated the women's ability to take appropriate actions and commence the integration of diabetes management as part of their everyday routine. By challenging health professionals, friends, family members and the controls placed upon them, the women began to experiment outside the parameters of their diabetic regime. In an effort to achieve normalcy in their lives the participants assessed the risks and benefits of diabetic self-care management decisions. Although they described following their diet, activity schedule and monitoring regime many women talked about cheating.

Cheating was a strategy that the women used to exercise some power over their situation and to normalize their everyday life. The women described how they would test the limits of their diabetic regime by eating forbidden foods or neglecting to self-monitor at prescribed times. Cheating in this context implied violating the regulations of diabetic management and has been reported in previous research conducted on people dealing with diabetes (MacLean &Goldman, 2000; Mitchell, 1998). In their study examining the lifestyle changes for women with Type II diabetes Whittemore, Chase, Mandle, & Roy (2002) concluded the need for flexibility in meal planning. Food cravings and exposure to temptations were the basis for intermittent lapses or cheating on the diet. Rather than an illustration of non-compliance these rebellious actions illustrated a means for the women to regain some level of control. Some women were tempted to falsify blood sugar results to avoid negative repercussions from their physicians. Thoughts of altering extreme blood sugar results were meant to circumvent continual control by others. These actions were similar to those reported in a study by McLean & Oman (1988) that explored the quality of life for persons living with diabetes. Their findings depicted how

persons with diabetes would at times intentionally choose to pursue actions that are contradictory to diabetes management.

Time was a key element for the successful management of their diabetes and for some women having only short period to adjust was considered a detriment. The women described how their familiarity with diabetes and its management grew over time, resulting in increased feelings of inner strength as they came closer to term. As their pregnancy advanced the women slowly became re-united with their body and the self-body relation became less adversarial. The women's increasing intuitive knowledge about managing their diabetes sanctioned less rigidity and more flexibility in carrying out their diabetic regime. Diabetes self-care became routine, habitual and integrated into their new sense of being. Near the end of their pregnancy the women had gained an inner sense of strength that facilitated their ability to make autonomous decisions regarding their pregnancy. The women described a process of overcoming the earlier challenges of managing diabetes and through trial and error learned to find a balance between being controlled and taking control.

The change that the women underwent as a result of their diabetic experience was evolutionary and depicted their eventual adaptation to the diabetic management regime. The transformative nature of chronic illness and its impact on the individual has been reported in previous research. For example, in a study by Paterson, Thorne, Crawford & Tarko (1999) it was suggested that in response to a threat to self-identity that results from a chronic illness experience, an individual undergoes a restructuring of self. These researchers describe diabetes as a transformational experience where the overall impact of the disease is influenced by the person's altered cognitive and affective response to disease. Coping with a chronic condition involves a shift from being a victim of circumstances to becoming a creator of circumstances (Patterson, et al., 1999). In a similar manner the women in this study described how over time the initial negativity and intense impact of gestational diabetes waned as they gained knowledge and skills about the condition. Once the women affirmed their diabetic state they could take action to regain control of their situation.

Women experiencing high-risk pregnancy assume power if they feel confident that they understand the issues involved and could make a choice that would maintain

their sense of balance (Levy, 1999). Increased knowledge of diabetes, enhanced competence in diabetic self-management, increased awareness of their bodily responses and success in predicting their blood sugar was associated with the women feeling that they were in control versus being controlled by internal forces. Taking control for these women was an intrinsic process that involved the women's perception of the impact that the necessary changes would have on themselves, their families and their infants. Achieving good diabetic control led to the women feeling strengthened and in charge of their situation.

Using grounded theory to explore the life style changes that women experience with Type II diabetes, Whittemore and associates (2002) described the establishment of new health pattern that involved awareness of personal vulnerability coupled with the women's acknowledgement of having diabetes. Self-exploration and experimentation contributed to women's diabetic regime becoming habitual over time.

In their middle-range theory on experiencing a life transition, Meleis, Sawyer, Im, Hifinger-Messias, & Schumacher (2000) noted a sense of wisdom arise from individuals' cumulative knowledge and understanding of their lived situations. The exercising of wisdom was evident in a person's "level of understanding of the different processes inherent in diagnosis, treatment, recovery, and living with limitations; in the level of resource utilization; and in the development of strategies for managing" (p. 25). Lived time for experiencing gestational diabetes, to gain both personal and scientific knowledge served to instill a sense of empowerment and internal wisdom. Internal power was exercised as the women voiced their ability to choose to take action in managing their diabetes and be in control.

The French philosopher, Michel Foucault (1980) offers a postmodern view of power that facilitates our understanding about the use of the women's internal power to rise up and take control of their diabetes. Foucault asserts that as individuals we are not powerless. He suggests that power is everywhere and is not possessed by a unitary, dominant agent but is found distributed throughout complex social networks. It is not given nor exchanged but always exists in our actions. Power and knowledge are interwoven and viewed as mutually constituted. As the birth of their baby neared,

the women had enhanced and exercised their power from the scientific and personal knowledge they had gained from their pregnancy experience. They were empowered to take action to choose how they would control their diabetes. However the precursor to action was the women's demonstrating internal acceptance of having diabetes and competence of its management.

In her longitudinal study Corbin (1987) examined how chronically ill pregnant women managed the medical risks associated with their pregnancy so that they could increase their chance of having a healthy baby. Pregnant women with a chronic condition engaged in a process called "protective governing" that consists of assessing, balancing and controlling. The strategy the women used to cope with gestational diabetes had similar characteristics to the process depicted in Corbin's model of protective governing. Throughout the pregnancy the women considered and weighed the benefits and risks of diabetic self-care on the health and well being of themselves and the fetus. The women's judgments about appropriate actions to take in diabetic self-care were based on blood glucose levels, reactions of family members, friends and health professionals, outcomes of prenatal assessments, and their own need to enjoy their pregnancy.

Using trial and error the women initially tried various strategies to manage their blood sugar while considering the consequences. They entered a process of balancing the forces of being controlled with taking steps to regain a sense of control. The realization of the stringent nature of gestational diabetes was a pivotal point of the women's diabetic self-care. They choose to take responsibility for their diabetic management and in doing so reached a balance in their lives by establishing a diabetic regime that worked for them.

Uncertainty

Although pregnancy is a normal phenomenon in women's development, uncertainty is considered a universal characteristic of being pregnant. Mercer (1995) suggests that in dealing with pregnancy and impending motherhood a woman's sense of normalcy is disrupted and she will inevitably encounter uncertainty and vulnerability. Uncertainty has been identified as "the inability to determine the meaning of events and occurs in a situation where the decision-maker is unable to

assign definite values to objects and events and/or is unable to accurately predict events" (Mishel & Braden, 1988, p. 98). Mishel's theory on uncertainty suggests that its management does not involve its elimination but rather its integration into one's life view.

For the women in this study life, as they knew and lived it, abruptly changed at the time of being diagnosed. Related to the loss of the women's "taken for granted" world was a heightened uncertainty that affected their perception of self and their pregnancy situation. The women described living a pregnancy characterized with many unknowns including potential adverse outcomes regarding the health and wellbeing of themselves, their pregnancy and their child. A sense of foreboding and concern emerged in the women's thoughts and continued into the early postpartum period. Throughout the pregnancy the mothers' angst and fear of possibly causing harm to their fetus or themselves escalated.

For these women the diminished control of their bodily responses while pregnant was associated with a heightened uncertainty about the future health and well being for themselves and their anticipated child. Their uncertainty centered on the nature of gestational diabetes, namely, its symptom unpredictability, its unknown effects on the future health and the outcome of the pregnancy and its known association with Type II diabetes. As the women coped with the elusive nature of gestational diabetes and variable blood sugar levels their feelings of uncertainty escalated. Extreme blood sugar levels elicited increased fear and concern for the well being of the baby. Although their feelings of uncertainty abated at the birth of a healthy baby many unknowns persisted into the postpartum as the women wondered about their own mortality and/or any future deterioration of their health.

The women constantly wondered if all was progressing well for their baby and sought reassurance through blood glucose monitoring. Validation that they were "doing good" in terms of their diabetes self-management was provided by self-monitoring, undergoing frequent prenatal surveillance, and obtaining feedback of progress by health professionals. Knowing their blood glucose levels determined their success in maintaining their blood sugar levels within the recommended range. Attending the diabetic clinic for necessary follow-up diabetic and medical care was

described as both supportive (their needs were acknowledged and addressed) and stressful where they felt evaluated and judged by health professionals. In contrast to their expectation that health professionals would show understanding if their blood sugar levels had been high, some women felt chastised by their health professionals and somehow to blame. The women would reflect on their past actions seeking a reason for any abnormal blood sugar values. Their questions caused feelings of guilt in the women. Were they somehow to blame? Does this mean their diabetes is worse? Will the baby be harmed? How would they know with any certainty?

Uncertainty acts as a force that can lead a person to be creative and take a new perspective on life (Mishel & Braden, 1988). When dealing with uncertainty in illness, Mishel and Braden suggest that as a person becomes more knowledgeable and skilled with the illness the initial perceived uncertainty associated with the complexity of care diminishes. Penrod (2001) describes uncertainty as dynamic and mediated by passage of time and any change in a person's perception of circumstances. As the women became more knowledgeable about gestational diabetes and competent in its management their feelings of uncertainty decreased. They felt in control of their situation.

To cope with being both pregnant and diabetic the women needed to accept the challenges associated with having developed diabetes. They felt in a position where there wasn't any other alternative. Having diabetes was viewed as just the way things were at the moment and that forced some women to make the decision to take control of their situation and deal with their diabetes. For some women this meant relinquishing some control to others, namely the health care professionals, to ensure a positive pregnancy outcome.

The women's perceived loss of control was related to their felt uncertainty about their situation. The women's decision to take control altered their perception of selves and their ability to effectively manage their diabetes. To lessen their perceived uncertainty associated with having gestational diabetes the women sought information about diabetes, engaged in diabetic self-care and valued the constant monitoring.

In an investigation of research where uncertainty during the childbearing process was explored, uncertainty was classified into three main areas, namely, reproductive uncertainty, waiting uncertainty and diagnostic uncertainty (Field, Marck, Anderson &McGeary, 1994). Waiting uncertainty is described as the feeling of tension and anxiety associated with waiting for the birth of the baby and waiting for results of any medical surveillance. This sense of waiting has relevance for the women in this study. Feelings of anguish accompanied the wait for the results of medical tests, the birth of the baby and any indication that the diabetes had been resolved postpartum. Waiting uncertainty didn't completely cease after giving birth as the women's attention shifted towards their future health and the possibility of diabetes re-occurring. Would they be permanently diabetic some day? Would their child develop diabetes? Diagnostic uncertainty is related to the imprecise nature of prenatal tests or the inability to predict outcomes accurately. Ambiguity and unpredictability characterize this category. Throughout the pregnancy the women remained unsure if they had been able to maintain good control of their blood sugar and no harm had been bestowed on their baby.

A high-risk pregnant woman's vulnerability is related to experiencing the uncertainty of maternal and neonatal outcome, regardless of her efforts (Mercer, 1990). These women talked openly about their fears and the measures they employed to alleviate them. The reproductive uncertainty expressed by the mothers was related to their labor and delivery. Many feared having a large baby and a long painful labor. Continuous blood glucose monitoring and surveillance by others became allies to these women and helped to minimize their uncertainty. Knowledge that their blood sugar levels were within the normal range was a source of comfort and meant that they were in good diabetic control. Their uncertainty and vulnerability was not resolved until their babies were born and shown to be healthy. Giving birth to a healthy small baby was an indicator that they have done a good job at carrying out their moral responsibility of being a good mother.

Uncertainty in childbearing is exemplified in the themes of vulnerability, inner dialogue, search for care, and living through possible motherhood (Field, Marck & Bergum, 1994). The initial diagnosis of gestational diabetes was the pivotal point

where the women's lives had changed and they felt more vulnerable to harm. To be vulnerable means being open to attack or damage by others (Merriam-Webster,1997). In an effort to decrease their vulnerability the women purposely sought out external sources of information for reassurance about their pregnancy progress. Many turned to printed educational resources, family members, friends and health professionals for support and advice. Experiential knowledge in addition to scientific information provided an inner strength that facilitated their success in managing their pregnancy and diabetes. The women developed an intrinsic sense of how things were developing personally, which allowed them some flexibility in following their diabetic regime.

Responsibility and control

Pregnancy and childbearing are considered to be the responsibility of the individual agents who are capable of making key decisions that will influence the well being of the pregnant woman (Talbot, Bibace, Bokhour & Bamberg, 2001). The women expressed a moral obligation not to be complacent in managing their diabetes. There was an overwhelming moral obligation to be vigilant in their management of the pregnancy and their diabetes. For example, they stressed the need to be cautious by closely watching what, where and when they ate. Their day-to-day activities could no longer be taken for granted or occur spontaneously. Life with gestational diabetes was a highly structured one that was calculated and dictated by clocked time. Questions arose, such as, When did I eat last? Is it time to test my blood glucose level? Is it time for another insulin injection? Can I go to that party? The women used the knowledge gained from attending diabetic classes, reading books and asking questions to facilitate their diabetic management and continue their everyday life in as normal a manner as possible. Making the prescribed lifestyle changes to comply with the diabetic regime was perceived as not having any choice. It was something that they just had to do. Their responsibility to protect their fetus from any adverse effects took precedence over everything else. The assertion, "that this is just the way it is. Don't fight it, join it" was present in their stories.

It was this acknowledgement of not having a choice in this matter, that is, diabetes is here for the time being, that provided the women a sense of personal

power. Control of their situation was achieved through their decision to deal with their diabetes. Taking control involved doing what is right for the well being of their anticipated child and themselves. Their sense of taking control was demonstrated by their decision to learn about diabetes management, follow the diabetic regime, monitor their blood sugars and stay cognizant of their bodily responses.

Accompanying their diagnosis of gestational diabetes was an exaggerated sense of accountability and responsibility towards the welfare of their fetus. The following excerpt of a poem depicts a mother's determination to protect her fetus from the perils of the outside world and keep it safe. The words remind me of the intense responsibility felt by the women in this study towards the well being of their fetus.

To an unborn infant

Be still, sweet babe, no harm shall reach thee,
Nor hurt thy yet unfinished form;
Thy mother's frame shall safely guard thee
From this bleak, this beating storm.

Author: Isabella Kelly, *Talking of mothers: Poems for every mother.*

The women initially relied on the authority and expertise of the health care team and rigidly adhered to their prescribed diabetic regime in the early phase of their diagnosis. The women's primary focus was on securing information about diabetes and obtaining the necessary medical care to keep their fetus safe from harm. Levy (1999) suggests that to deal with changes associated with pregnancy, women will seek and use information to protect and keep in balance the interests of herself, fetus, partner and others.

Reva Rubin (1984) explored the pregnancy experience and outlined a theory that describes how women develop readiness for mothering through the accomplishment of four developmental tasks: 1) to ensure safe passage for herself and her baby; 2) to secure and ensure social acceptance of herself and her child by significant others; 3) to commit the image and identity of self as mother and binding in to the child; and 4) to give of oneself, that is to explore the meaning of the transitive act of giving/receiving and of giving of one's self on behalf of another. In

their study of women experiencing a high-risk perinatal situation Stainton, McNeil & Harvey (1992b), conclude that although women work on the same developmental tasks as described by Rubin, their tasks were altered. "Their maternal experience is changed from the culturally expected to one in which unknowns dominate and feelings of control, involvement, and self-reliance deteriorate" (Stainton et al., p. 116).

In pregnancy there is the implication that a mother's connection with her fetus represents an intense relationship of reciprocity. In the pregnant state there is a heightened awareness of the woman's vulnerability and normal and everyday events are perceived as being dangerous (Mercer, 1995). There is a societal expectation that the high-risk mother gives the ultimate for the sake of her anticipated unborn child. Gestational diabetes management perpetuates medicalization of the childbearing experience. Viewing the protection of the fetus as common sense supports an ideological rationale for intervention into a woman's pregnancy, either through the application of invasive technologies or from social monitoring and surveillance.

To seek and ensure safe passage throughout pregnancy and childbirth, more was involved than the women obtaining obstetrical and prenatal services, though these were significant to increasing the women's comfort level. Mercer (1995) suggests women's behavior to ensure safe passage is culturally defined and is sensitive to evolving knowledge and social change regarding reproductive health. For these women, their decision to undergo prenatal screening tests were based on weighing the benefits of the information provided by these tests such as providing assurance regarding the well being of the anticipated child. Attending the clinic and heeding the advice of the health professionals were considered important for the care of the expected baby.

Kent (2000) writes, "becoming a mother is associated with fully becoming a woman, that is an individual realized as a woman by caring for others (her unborn child) and experiencing the subjugation of her interests and needs to others" (p. 106). The loss of self that is associated with becoming a mother is compounded for pregnant women who encounter gestational diabetes. The result of submitting to recommended plan of care resulted in an unsatisfactory labor and delivery experience

for many of the women. Many were induced prior to their date as a measure to prevent a large baby. Other pregnancies ended in cesarean section, which was for some women disappointing. Emphasis is on doing for the sake of the fetus while putting everything else on hold. The women in this study remained acutely aware of the affects that their actions or in-actions could have on their fetus.

Although the women were initially surprised by their diagnosis many spoke of having anticipated it. Their expectations were based on factors such as having been overweight prior to conceiving, not exercising, having had gestational diabetes previously or having a positive family history of diabetes. They understood the intricate nature of their relationship with their fetus and were ever conscious of potentially endangering it and themselves. Only by making healthy choices and engaging in appropriate behaviors could they safeguard their health status as well as that of their fetus. For those who challenged the stringent regime by eating forbidden foods or failing to test their blood sugars at prescribed times justified their actions through faith that they intuitively knew that no harm would come to their fetus.

Findings from previous studies suggest that diabetes in pregnancy is associated with long-term effects on the self-perceived health status of pregnant women and their anticipated child (Feig, Chen, & Naylor, 1998; Sjogren, Robeus, & Hannson, 1994). Similar perceptions of long term health outcomes were evident for the women participating in the present study. Concerns centered on the potential impact that gestational diabetes might have on the future health of both themselves and their baby. In contrast to the previous research on pregnant diabetic women, diabetes was characterized as having been beneficial. Although they worried about developing Type II diabetes later in life the women felt healthier and that they were now living a healthy lifestyle. Encountering gestational diabetes was deemed a positive influence by some of the mothers. Gestational diabetes acted as a "wake up" call and a catalyst for making permanent life style changes for themselves and their family.

Research has been conducted to examine the psychological outcomes of women who are pregnant and diabetic. York, Brown, Armstrong-Persily, & Jacobson (1996) explored affect in diabetic women during pregnancy and postpartum. The

researchers noted that women with gestational diabetes exhibited higher anxiety and hostility than those who had pre-gestational diabetes. The greatest anxiety for the women was felt when gestational diabetes was initially diagnosed. Adjusting to their diagnosis and learning complex regimes and skills were considered contributing factors to any negative feelings. Although quantitative measures were utilized, the findings were supported by comments made by the women in this present study about the frustrations and fears associated with diabetes.

In a correlation study, Langer & Langer (1994) examined how intensified diabetic management, namely diet and insulin, affected pregnant diabetic women's mood. The relationship between treatment modality and emotional status and metabolic control and mood were analyzed using the Profile of Mood States-Bipolar scale. The authors concluded that intensified management of newly diagnosed gestational diabetes mellitus with insulin was not significantly associated with an increase in the women's anxiety or depression level. Insulin use did not in and of itself adversely affect the emotional status of women. They report that women who were prescribed very strict glycemic control were less distressed than those in poor control. The researchers also suggest their findings are indicative that the majority of pregnant women adapt readily to the unexpected diagnosis of gestational diabetes and their mood states were not adversely affected.

In a subsequent study using secondary analysis, Langer & Langer (2000) compared pregnancy mood profiles in women with gestational diabetes with those with pre-existing diabetes. Mood affect was found to be significantly associated with the level of glycemic control for the women with GDM. The women who expressed having poor glycemic control reported a higher level of depression than the women who considered themselves in good control as demonstrated by euglycemia. The researchers suggest diabetic care is more than providing information to the client. They posit that women with gestational diabetes mellitus and pre-gestational diabetes mellitus present with differing emotional levels warranting individualized treatment goals to enhance compliance and to produce positive maternal and neonatal outcomes.

Achievement of good diabetic control contributed to the positive affect expressed by the women about their pregnancy experience in the present study and provides support to the findings of Langer and Langer. Discovering that their blood sugar was being maintained within the recommended range was a source of relief. However the opposite was the case if the women encountered hyper- or hypogylcemia. Although the two previous studies suggest a woman's eventual adaptation to having diabetes, the results fail to capture the nature of the experience. The research tool was administered when the women were in their 37-38 week of gestation omitting any information about how they felt around the time of diagnosis or during most of the pregnancy.

The self-efficacy of the women in the present study regarding their diabetic self-management eventually increased yet the process they underwent was characterized by emotional turmoil and many challenges to overcome. For example, insulin was associated with sickness and the prospect of requiring it to control their blood sugars was worrisome. For many women, insulin administration was synonymous with taking medication an action frowned upon during pregnancy. In the present study the women expressed the desire to avoid insulin treatment but those who required insulin adjusted to its administration over time.

Previous studies where women's emotional adjustments and well being to having gestational diabetes were examined contrasted with the experiences of the women in this study. In their study on maternal depressive symptoms in pregnant women experiencing gestational diabetes, preterm labor or a normal pregnancy Chazotte, Comerford-Freda, Elovitz, & Youchah (1995) report the presence of depressive symptoms in all three groups but no significant difference between them. The researchers also found that maternal-fetal attachment was not adversely affected. In the present study the attachment to the baby was strengthened as evidenced by the heightened sense of accountability and responsibility by the mother towards her baby's well being. The unborn child was always foremost on the minds of the mothers as they tried to manage diabetic self-care. Although not explicitly measured, feelings of intense depression were not evident in the women's stories of living with gestational diabetes.

When their babies were born the women had reached the end of one stage of the childbearing process. The birth of their baby marked the summit of the mountain they had been climbing. After delivery, knowing that their baby was healthy and their diabetes was gone was met with intense relief. They were instantly free from the externally imposed constraints. However the freedom they felt surrounding the absence of diabetes and constant surveillance was short lived. Many of the women had known risk factors for gestational diabetes prior to becoming pregnant and experienced extra risks prior to birth. The concerns they had for their future health and that of their baby's continued into the postpartum period. The mothers acknowledged the uncertain future in terms of the possibility of developing diabetes later in life or in a subsequent pregnancy. Many were troubled with the thought that their child might develop diabetes later in life. However they felt transformed and rather than turn back, wanted to stay the course they had discovered through living with diabetes. Motivation was high to permanently entrench the lifestyle changes that had been in place for the past few months into their daily routines.

These women's experience of being pregnant and diabetic reveals the complex nature of a pregnancy that is suddenly labeled "at risk". The themes elicited from the stories remind us as health professionals that after the initial crisis surrounding the diagnosis of gestational diabetes the women will need to learn new ways to adapt as their pregnancy advances. In contrast to a normal pregnancy the women are suddenly dealing with new issues of internal and external control of their pregnant body and pregnancy. Relationships with family members and health professionals become problematic as the women try to regain some control. Diabetes was viewed as both a risk as well as a benefit for the pregnant woman and her anticipated child. The overall impact of diabetes on their lives was assessed to help determine how best to commence and maintain diabetes self-management.

Acknowledging their diabetes led to affirmative measures in finding a balance between fulfilling their needs to live a normal life and enjoy their pregnancy while adhering to a prescribed diabetic regime. Through the process of living with gestational diabetes it eventually became integrated as part of their being. The women increased their knowledge of their body and capabilities to take action. They

moved from a position of felt powerlessness to one of motivation and personal strength. They were challenged to regain control of their lives, to learn new skills and in the process developed a new way of being. The knowledge they gained about themselves and their body and the decisions they made about their health were made possible from having experienced gestational diabetes. In this study the fact that the women considered their experience with gestational diabetes as motivational in terms of maintaining healthy lifestyles has significant implications for implementing health promotion and education in childbearing practice.

This research has led us to further understanding of the complexities inherent in women's experience of gestational diabetes. The findings validate and add to previous knowledge on women's experience of an "at risk" pregnancy. In contrast to other pregnancies these women are subjected to heightened control measures and as a consequence their self-determination was diminished.

The findings further support previous work on a person's adaptation to chronic illness, particularly diabetes. The women tried to achieve and maintain a balance between quality of life and compliance with their diabetic regime. They needed assurance of being in good control of their glycemic state to lessen the adverse affects on themselves and their anticipated child. In the process of adapting to having gestational diabetes the women developed a new way of being. Their encounter with gestational diabetes came as an indicator that they needed to make and could make changes in the way they conducted their lives. Additional questions about childbearing nursing practice are generated and provide a basis for developing appropriate and effective interventions for women facing gestational diabetes in pregnancy.

CHAPTER EIGHT

Conclusion

There are inherent problems in limiting our vision of childbirth to its technical, medical dimension. That vision of childbirth enables us to think only in terms of morbidity and mortality rates, and not the often wrenching social and person implications involved in childbirth management programs and technology (Rothman, 2000, p. 117).

I embarked on this research seeking a deeper understanding of how gestational diabetes is meaningfully experienced by pregnant women. My work began with the question, "What is it like to experience gestational diabetes?" The question arose from reflecting on my personal childbearing experience as well as my professional work as a nurse caring for pregnant women. The hermeneutic phenomenological approach used in this study uncovered the arduous process expectant mothers undergo when their pregnancy experience suddenly is interrupted as a result of a prenatal blood glucose screening test.

As I pursued this study I constantly discovered the intense need for women to converse with others about their pregnancy experience. Upon hearing about my research, women who I met casually proceeded to tell me about living with diabetes while pregnant. Women appeared starved for information on the emotional aspects of having diabetes during pregnancy. I encountered popular well-utilized Internet sites with discussion groups designed for pregnant diabetic women to reveal and share their pregnancy experience with others.

I am reminded of one mother who told me how difficult it was for her after being diagnosed to find the information she needed about gestational diabetes. Although many helpful resources on the physiological responses to diabetes and the technical and management aspects were available to her, this information failed to provide all that she desired. She spoke about the scarcity of material regarding the emotional and psychological characteristics of pregnancy induced diabetes. Her expressed need to reach out to other women who had similar pregnancy experiences was paramount. How is she supposed to feel? Are her feelings about self, her

pregnancy and the reactions of others normal? How will she cope with the many necessary life style changes? Another woman stated, *"the pamphlets and everything they gave you, you read and stuff but it doesn't help you very much in the sense of how you felt. Like I didn't have anyone to talk to about it. I know I went to the doctor's, I went to the dietician and the nurses and everything but how do you really talk to them and say, 'Gee, I'm really embarrassed because of this diabetes'"* (Barbara). How does she tell them how she really feels? Another woman exclaims, *"Don't try to fix it, let me talk about it"* (Diane).

The themes that emerged from these women's stories reveal the rich and multifaceted nature of gestational diabetes and the deep impact it had on the lives of the women who experienced it. The intensive diabetic regime and constant surveillance further emphasized societal norm towards the medicalization of pregnancy. The women's stories reveal an experience of living a controlled pregnancy, one in which the mothers tried to establish a balance in their lives and maintain a sense of normality. For the sake of their anticipated child's and own health and well-being the women acknowledged their responsibility for actively engaging in diabetic self-care. Although the women recognized the adverse impact of having had diabetes on their baby and their long-term health, the experience was also perceived as beneficial by many of them. Their encounter with and management of diabetes motivated the women to make healthy lifestyle choices that otherwise would likely have been left unmade. The knowledge the women gained about diabetes, self and body, both scientific and intuitive, was transformative and assisted in their decision to make and hopefully maintain long-term life style changes.

Pregnancy when viewed within the traditional medical paradigm is characterized as possessing some level of risk for the mother and her unborn infant. The decision to conduct a blood glucose-screening test during pregnancy was based on the individual woman who on becoming pregnant, presented with known risk factors for gestational diabetes. Many of the women acknowledged having certain risk factors, such as, being overweight, having a family history of diabetes, or having poor activity levels and eating habits when they became pregnant. However any personal knowledge regarding their potential for developing diabetes during

pregnancy was not in and of itself a potent motivator for many of the women to make any major changes in their lives to minimize these risks prior to their diagnosis.

Mauger (2000) notes, "each pregnant women is in a state of becoming. She is not what she was, she is not yet what she will become, and this makes her very suggestible and susceptible to the environment and the influence of others" (p. 28). Being told that they had gestational diabetes was consciousness-raising for many of the women. The diagnosis of GDM came as a shock and the women's thoughts about the impact of having gestational diabetes and associated risk factors had on the self, the pregnancy and particularly their fetus was brought to the surface. Complacency could no longer play a major role in their lives and women had to face the reality of their diabetes directly. As Northup (1998) aptly puts it when speaking of pregnancy, the women "picked up on all the societal fears for them" (p. 453).

As a consequence of being diagnosed with GDM, the women were subjected to a pregnancy experience that was determined to be at heightened risk warranting closer surveillance and monitoring. Use of technology emphasizes the "at risk" nature of childbearing and challenges women's perception of experiencing a normal pregnancy. Medical intervention and regimentation associated with the care of a pregnant diabetic woman provided the means for the health care team, family members and friends to exert additional power and control over the women and their pregnancies. Control by others and over the women's actions during pregnancy became entrenched through the establishment of reconstructed expectations and responsibilities of the women and the health care providers. To not take action and adhere to their diabetic regime and be closely monitored was considered by the women and others as acting irresponsibly. They also needed to reconsider their birth plans.

Health professionals have been given the authority (power) to define what is normal in the childbearing process. What falls outside the designated parameters of normality in pregnancy is labeled abnormal. Nursing practice is largely contained within the auspices of the medical model where acknowledge of risk, real or potential, is paramount. Risk for nurses and other health care providers evolves around the concern for the infant and maternal morbidity and mortality. Their aim is

to minimize or eliminate risk through the use of risk analysis and intervention measures. These strategies strengthen the potential of further categorizing pregnant women at some degree of risk rather than focusing on pregnancy being a normal life event.

The women's evaluation of their level of risk before, during and after pregnancy is embedded in their everyday lives. Being considered at risk by technological means is more encompassing for women and includes thoughts of morbidity and mortality for self and baby as well as social and psychological implications. By evaluating their choices involved in dealing with a diabetic pregnancy and any associated risks the women determined that compliance for the sake of their expected baby outweighed any alternative actions. Although they acknowledged having diabetes and adhered to the diabetic regime the women counterbalanced their actions by trying to maintain a sense of normality in their day-to-day lives. As one woman told me she still wanted to enjoy her pregnancy.

Many women considered having experienced gestational diabetes as a good thing. Their comments were puzzling to me at first. I remember wondering how can something that has been described as scary, stressful and filled with uncertainties be positive. Northup (1998) suggests that pregnant women are very powerful yet simultaneously very vulnerable beings. Pregnancy without diabetes is associated with control issues and dealing with many uncertainties and a heightened sense of vulnerability. The women in this study were vulnerable to the innocuous nature of gestational diabetes and the loss of personal control. Once the women accepted the reality of having diabetes, the known risks for themselves and their anticipated child had a positive effect in terms of making lifestyle changes. Acknowledging the risks involved for themselves and their fetus and determining what measures they could take to minimize the risks was beneficial and helped the women to regain a sense of control of their lives. They made the conscious choice to follow the prescribed diabetic regime for the sake of their baby and expressed the desire to maintain a healthy lifestyle into the postpartum period and to avoid diabetes in the future. As they became more skilled and knowledgeable about diabetes self-care they tried to

engage in diabetic self-care activities while maintaining some sense of normal routine.

Implications for nursing practice

The knowledge gained from this research study directs us to reflect upon our traditional care practices with childbearing women and their families, especially those who experience a pregnancy "at risk". Nurses and other health care professionals are challenged to acknowledge and appreciate the complex nature of gestational diabetes and its affect for the women who develop it. They have a crucial role in understanding how fostering the inner strength of the pregnant woman can act as an influential factor in her ability to feel in control of the diabetes and her pregnancy. While considering the known risks of GDM for mother and fetus, health professionals need to identify and implement strategies that will help normalize pregnant diabetic women's transition to motherhood and facilitate their enjoyment of pregnancy.

Based on the themes identified from the women's lived experience of gestational diabetes, nurses and other health professionals need to remain cognizant of the intense impact diabetes has on pregnant women's lives. A holistic approach to care that does not minimize the importance of the physical dimension of GDM but also includes the psychological, emotional, and spiritual dimensions is recommended. Over simplification of diabetes self-care management by the mother and her associated feelings needs to be avoided. Health professionals need to acknowledge the particulars of women's experience with diabetes and remain cognizant of the emotional impact, energy, time commitment, and financial burden it has for women and their families.

Soon after the birth of their infants the women discovered that the gestational diabetes had resolved itself. Although relieved that their blood glucose levels were found within normal range, many women wondered about the sudden end to the constant and intense medical surveillance. Postpartum presents a time of further change when the woman, in addition to adapting to her mothering role to her newborn, deals with physiological, emotional, and hormonal changes. The dietary and activity changes associated with achieving a normal blood glucose level is critical for these women to continue with postpartum to help prevent Type II diabetes in the

future or gestational diabetes in a subsequent pregnancy. However maternal follow-up care beyond six weeks postpartum is minimal for childbearing women.

Many of the women expressed the desire to maintain the healthy lifestyle they had acquired through following the diabetic regime during pregnancy. Postpartum fatigue, mood changes and the usual demands of adapting to a new baby may limit a woman's ability or willingness to keep up their changed lifestyle. Nurses play a major role in supporting and assisting women in their commitment to maintain a healthy lifestyle postpartum. Health promotion programs are required throughout the postpartum period to help identify and meet the long-term health needs of women who experienced gestational diabetes. These programs could include peer support groups for women.

The woman's family including its internal and external relationships is important part of nursing care. Family assessment facilitates the nurse's understanding of the characteristics, strengths and dynamic processes of the family unit. Spouses and extended family members are sources of support throughout the woman's pregnancy and can serve as partners in care. Nurses need to include family members in their assessment and care of pregnant women and respect their strengths, values, and attitudes. To remain focused solely on the pregnant woman as separate from her family limits the nurse's ability to help build family cohesion and mutual support during an anxiety-provoking event. A family centered approach to care acknowledges the complexity of family and its influence on how adjustments are made when an illness is encountered by one of the members. By caring for a woman with gestational diabetes in the context of her family the nurse is prepared to facilitate and support the coping and adaptation of the woman, the other family members and the family as a whole.

Many of the women possessed many of the known risk factors for gestational diabetes. Some of these factors, such as dietary habits and exercise levels, are modifiable. Primary prevention strategies to minimize these risk factors in pregnant women and non-pregnant women of childbearing age are essential. Programs such as proper nutrition and exercise could be geared to young pre-adolescent and adolescent girls.

When a woman is contemplating pregnancy, is pregnant, or is a new mother her particular beliefs and perceptions about health risks need to be identified and understood. It is critical for health professionals to be perceptive of how information about risk is communicated to the women and what words are used during prenatal education and postpartum follow-up. Words that are threatening or meant to force compliance are counterproductive and serve only to increase women's frustration and stress. To provide meaningful information to the woman about the risk of diabetes in pregnancy it is crucial to identify the woman's interpretation of risk in context of her daily life experience. Only then can nurses and other health professionals effectively support the pregnant woman as she attempts to engage in diabetes self care and experience a positive childbearing experience.

Pregnant women's stories need to be heard to facilitate our understanding how they are coping with their pregnancy and diabetes self-care. Unconditional respect for the lived realties of these women is needed as they try to cope with their diabetes and set self-defined goals. By being present with the pregnant woman, listening to her concerns and identifying with their challenges nurses can shift their focus away from the pregnancy itself and more towards the woman as a person first who is pregnant and has diabetes. Working in partnership with the pregnant woman, health professionals can assist in the development of a diabetic regime that is congruent to the woman's values and priorities and fits within the context of her life.

Nurses can play a crucial role in empowering women to draw upon their inner strength and achieve a successful adaptation to their diabetic pregnancy. Interventions are needed that will assist women to integrate what they intuitively feel and know from their pregnancy experience and what they learn from health professionals and other resources into their everyday life routine. Nurses need to determine, without criticism and judgment, relevant strategies that will facilitate the actions women take to control of their diabetes management. For example, work with the woman to determine ways she can adjust the prescribed dietary changes to accommodate her everyday routine. Recognition that pregnant women are autonomous beings, who, with the appropriate knowledge, are capable of making decisions that are in the best interest of themselves and their unborn infant, is needed.

Acknowledgement and respect of the women's human-ness is paramount in providing nursing care. In addition to the required medical interventions associated with the physical effects of a diabetic pregnancy the emotional, psychological aspects need to be acknowledged and addressed.

To accomplish this we need to create a moral space, that is, a space to ask questions, listen, and act. By moral space I mean that in the provision of care an environment is constructed where a partnership is fostered between the woman and the health care provider. Health professionals need to be prepared to listen and the women need to feel that they are being heard to foster the latter's well being. This involves establishing a relationship between the woman and nurse that espouses engagement, trust, responsiveness and mutual respect. The nurse when interacting with the woman needs to express a genuine concern for the woman's well being. Through listening and having a caring presence the nurse is better equipped to be supportive of the women's struggles as she copes with the fears and challenges associated with having gestational diabetes. Listening facilitates the nurse's ability to effectively reflect the woman's thoughts and feelings associated with have gestational diabetes and gain a genuine understanding of what the woman is experiencing. By listening and being attentive to the woman's needs the nurse comes to know the woman as a person who has developed gestational diabetes rather than the diagnosis of a diabetic pregnancy.

The nurse in providing care learns from and with the woman about her experience of gestational diabetes. In this way nurses become aware of what are the needs of these women and their families and identify ways to assist them as they struggle with diabetes self-care. Nursing care would be based on the scientific knowledge of diabetes as well as the knowledge gained from the caring relationship with the pregnant woman and her family. Using this approach the information given to the women by the health care team would be more meaningful and facilitate the women to make choices in their care that was judged right for them.

Recommendations

1. Implement measures, such as, peer support groups, to provide women who encounter diabetes in pregnancy the opportunity to share their experiences

with others. Develop resources (printed materials, Internet documents) with testimonials on life with gestational diabetes.

2. Facilitate the integration of lifestyle changes related to diabetes management into women's usual life style patterning by focusing on women's individual adaptation process towards diabetic self-care.
3. Use a holistic experiential approach to care rather than merely information giving about diabetes and its management,
4. Facilitate normalization of the diabetic pregnancy by supporting measures the women take to enjoy their pregnancy while adjusting to diabetic self-care.
5. Remain cognizant of the woman as a person with distinct needs, desires and strengths.
6. Include postpartum follow-up programs as part of diabetic preventive education.
7. Implement educational program on nutrition and activity for women in their childbearing years as part of primary prevention.
8. Include family members especially spouse in planning and implementation of diabetic care.

Implications for nursing research

This study illuminates the "lifeworlds" of these women during a diabetic pregnancy experience and in the process many questions were elicited. My hope in relaying these stories was to inspire reflection on the phenomena of an at risk pregnancy in a new and different way.

Diabetes acted as a catalyst for making behavioral changes for many of the women. Questions arise on the longevity of the women's motivation to making lifestyle changes, particularly dietary ones. There is a paucity of research on whether the dietary and activity changes made by women to manage gestational diabetes become a permanent part of their lifestyle after the birth of their baby. Longitudinal prospective studies with women after childbirth are needed to identify factors associated with the women's continuation of a healthy lifestyle and diet. What support measures are needed to support the maintenance of life long lifestyle changes that many of the women expressed adopting as a result of ? Would adherence to

healthier life style be more probable in those who had intensive diabetic management than those who managed their diabetes by diet only? What impact would previous encounters with gestational diabetes have on women making long-term lifestyle changes? What primary care measures could be implemented to prevent the development of gestational diabetes in subsequent pregnancies? The knowledge gained by addressing these questions will facilitate the development of effective health promotion programs for childbearing women at risk for Type II diabetes. Other research opportunities involve determining if instituting lifestyle changes (diet and exercise) early in pregnancy in women who have known risk factors for gestational diabetes would help prevent the development of GDM.

An important area for continuing research would be the further exploration of being 'in control' as opposed to 'being controlled' when facing an at risk pregnancy. What is the experience of being in control? What factors are associated with women controlling a high-risk pregnancy? Are issues of control for women with an at risk pregnancy different or similar to those experiencing a pregnancy not at risk?

Many women described over time feeling more comfortable with having diabetes and diabetes management. More research is needed to explore what factors facilitated women's comfort level when dealing with diabetes in pregnancy. What factors hinder their feelings of comfort?

The conflict revealed between the women and their spouse, family members, friends, and health professionals needs further research to explore what encompasses a caring relationship in the context of a high-risk pregnancy. Pregnancy is a family event and the findings from this study suggest further research be conducted that focuses on family members, particularly the father. What is the pregnancy experience like for him?

This work offers a view of only one component in our understanding of the transition to motherhood for those women who encounter an "at risk" pregnancy. Some of the mystery has been uncovered but new possibilities have emerged that need further exploration to fully understand the lived experience of gestational diabetes. The challenge continues.

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Appendix A

Letter of Invitation

Dear Parent:

Pregnancy can be one of most memorable events for a woman and her family to experience. Sometimes things can happen during a pregnancy that are unexpected. I am a graduate student in nursing and interested in understanding what it is like to have gestational diabetes. I would like to talk with women who are pregnant and have gestational diabetes and find out more about their experience. By having a better understanding of this pregnancy experience for women, health care providers can improve the care they give.

If you are interested in being part of this study or learning more about it please call me at (780) 492-0031 or (780) 484-8703.

Thank you,

Marilyn Evans RN MN
Doctoral Candidate
Faculty of Nursing
University of Alberta
Edmonton, Alberta

Appendix B

Information Letter for Study Participants

Principal Investigator:

Marilyn Evans
PhD Candidate
Faculty of Nursing
University of Alberta
Edmonton, Alberta
(780)492-0031

Supervisor:

Dr. Beverley O'Brien
Associate Professor
Faculty of Nursing
University of Alberta
Edmonton, Alberta
(780)492-8232

Project Title: Gestational diabetes: Uncovering the meaning of an "at risk" pregnancy

Purpose:

This is a study to describe and interpret women's pregnancy experiences. I am interested in understanding what it is like for women to have and be treated for an at risk pregnancy.

Procedure:

If you have gestational diabetes you can be part of this study. If you do, I will ask you to take part in one or more interviews. Each talk will last about one hour and will occur at a time and place convenient to you. I will ask you about your pregnancy experience. Being in this study will not take more than four hours of your time. I would like to tape record and type the talks. I will turn off the tape recorder whenever you want me to not record a part of you talk. You may ask me to leave parts of your interview out of the study. I will give you a copy of the typed interview if you want.

If you agree, I may use the typed interviews for another study in the future. I will seek approval from the appropriate ethical review committee before beginning another study.

Benefits and risks:

There are no known risks for you if you decide to be part of this study.

Confidentiality:

Your name and any other information that could say who you are will not appear in this study. You will be given a code name if you agree to take part in this study. I will keep your consent form in a locked cabinet separate from other information that could identify you. I will keep all the tapes and typed interviews and any other written information about you in a locked cabinet. Only myself, the members of my research committee and the person who may type the interview will listen to the tapes

or read the typed interviews. I will keep the tapes and typed interviews for at least seven years.

I may publish or present the study's findings. I will not use your name or any information that may identify you.

Freedom to withdraw:

You do not have to take part in this study unless you want to. You can drop out at any time just by telling me or my supervisor Dr. Beverley O'Brien. The medical or nursing care that you receive will not change if you decide to leave the study.

Right to refuse to answer a question:

You do not have to answer any question that you do not want to answer.

If you have any questions about the study you may call me at (780) 492-0031 or my supervisor Dr. Beverley O'Brien at (780) 492-8232. If you have any concerns about any aspect of this study, you may call the Patient Concerns Office at the Capital Health Authority (780) 492-1040. This office has no affiliation with the researcher. My supervisor

Consent Form

Project Title: Gestational diabetes: Uncovering the meaning of an "at risk" pregnancy

Principal Investigator:

Marilyn Evans
PhD Candidate
Faculty of Nursing
University of Alberta
Edmonton, Alberta
(780) 492-0031

Supervisor:

Dr. Beverley O'Brien
Associate Professor
Faculty of Nursing
University of Alberta
Edmonton, Alberta
(780) 492-8232

Do you understand that you have been asked to be part of a research study?
Yes No
Have you read and received a copy of the Information Sheet and consent form?
Yes No
Do you understand the benefits and risks involved in taking part of this study?
Yes No
Have you had the chance to ask questions about this study?
Yes No
Do you understand that you are free to withdraw from the study at any time? You do not have to give reason and it will not affect your care?
Yes No
Has the issue of confidentiality been explained to you?
Yes No
Do you understand The Alberta Health or your regional health authority may be contacted for information about you and your baby?
Yes No
May Marilyn Evans keep typed interviews for use in the future?
Yes No

This study was explained to me by: _____
I agree to take part in this study.

_____ _____ _____
Signature of Participant Witness Date

_____
Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____ _____
Signature of Investigator Date

Appendix C

Sample Demographics

Name	Age	Delivery	Gender		Birthweight
Audrey	38	Vaginal	Boy	37 weeks	7lb 7oz
Barbara	32	C/S	Girl	39 weeks	8lb10oz
Cathi	30	C/S	Boy	39 weeks	7lb 2oz
Diane	32	Vaginal	Girl	40+weeks	7lb 5oz
Ellen	35	Vaginal	Boy	40 weeks	7lb 8oz
Francine	23	Vaginal	Boy	39 weeks	5lb 14oz
Gretchen	26	Vaginal	Boy	39 weeks	9lb 10oz
Helen	34	Vaginal	Boy	40 weeks	7lb 14oz
Irene	na	C/S	Boy	39 weeks	7lb 15oz
Jane	30	Vaginal	Girl	40 weeks	7lb 11oz
Lynne	30	C/S	Girl	39 weeks	6lb 1oz
Kathryn	32	C/S	Boy	36 weeks	8lb 5oz

Appendix D

Guiding Interview Questions

Can you tell me what it was like when you found out that you had gestational diabetes?

How did your family and friends react?

Tell me about your decision to have the blood glucose-screening test.

What other prenatal tests have you had?

Describe some of the changes that you have had to make with this pregnancy.

What thoughts do you have about this pregnancy, yourself, your baby?

What have you found helpful?

What have you found not helpful?